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Economic Impact of Labour, Income Security, and Health Programs on Family and Friend Caregivers for Adults with Mental Illness in Canada

by

Linda Joyce Hopper Cook

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March 29, 2007

This study is dedicated to

My father who taught me how to think

My mother and aunt who taught me about caregiving

My husband and children, without whose encouragement it would not have happened

And Norah Keating and all of my committee who taught me to new questions to ask.

ABSTRACT

Mental illness is a widespread and significant concern affecting not only the ill individual but also family/friend caregivers. Growing costs to the public purse for health care and disability services have increased pressures for providing "costless" care in the community. The etiology, course, severity, treatments, and side effects of many mental illnesses can result in high economic costs for family/friend caregivers. The purposes of this study were to identify economic costs that family/friend caregivers incur, associations between costs, relationship and gender, and whether public programs effectively reduce these costs. Methods included both quantitative analysis and policy analysis.

This study found that caregivers in many relationships experienced high costs. Gender in and of itself did not predict high individual costs, but predicted caregiving. Daughter, mother, and husband caregivers were found to be especially at risk for multiple high costs. Policy analysis of public programs in labour, income security, and health domains in two regions of Canada showed that little direct or indirect reduction was available for employment-related, out of pocket and unpaid labour costs to caregivers. In addition, policy treated relationship with the caregiver differently for parents and husbands than for other caregivers resulting in potentially higher costs. Program assistance to care receivers that could indirectly reduce caregiver costs frequently depended on disability definitions that did not fit mental illness well. Regional differences in social and disability assistance, prescription drug plans, allied health services, and medical transportation programs could result in significant differences in the amount of caregiver costs in different parts of the country.

Two policy recommendations were included: removing relationship as an eligibility criterion for programs that can reduce caregiver costs and reworking of disability policies for consistency and applicability to persons with mental illnesses. This study contributes to caregiver cost diversity knowledge and includes an adapted caregiving costs taxonomy.

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CHAPTER 1: BACKGROUND

Mental illness is a serious concern worldwide and it impacts the lives of many Canadians. It has been estimated that the direct cost in public expenditures to Canada for this category of diseases is over 4.6 billion dollars per year (Health Canada, 2002b). Only cardiovascular diseases rank higher in direct costs to the health care system (Standing Senate Committee on Social Affairs, Science, & Technology, 2003).

However, these data provide only a part of the story of costs related to care of persons with mental illness. Studies about the economic costs of illness have often failed to include the costs to the people who provide the bulk of the necessary care in the community (e.g., Clark, Ricketts, & McHugo, 1999; Reinharz, Lesage, & Contandriopoulos, 2000; van den Berg, Brouwer, & Koopmanschap, 2004). Costs to caregivers exist apart from costs to the health care system and have impacts on caregivers' lives and on society as a whole. Although some authors include family costs as a part of indirect costs of care (Andersson, Carstensen, Levin, & Emtinger, 2003; Chiu, Tang, Liu, Shyu, & Chang, 1999; Gray & Chapman, 2001; Mature Market Institute, 1999), conventional assumptions for calculation of indirect costs include only costs borne by society through losses of productivity of the person who has the illness (Stephens & Joubert, 2001) or costs to the legal system (Das Gupta & Guest, 2002). Calculating in this manner ignores costs for caregivers, which can lead to substantial underestimation of overall costs to society as a whole (Grunfeld & Glossop, 1997; Health Canada, 2002b).

It has been estimated that approximately 20% of the Canadian population will experience some type of mental illness during their lifetime and that those who do not personally experience mental illness will be affected either directly or indirectly by the mental illness of others (Health Canada, 2002d). Several types of disease exist within the category of mental illness and these can have varied costs for the persons experiencing them and for those who assist them. However, the centrality of the mind for all of life's functioning sets these particular illnesses apart from others as particularly disabling.

Although much of the care of persons with mental illness falls to families and friends, the economic costs to these caregivers remains largely hidden. According to the World Health Organization (2001) costs to caregivers of persons with mental illness are both "undefined" and "hidden" throughout the world, because of a lack of detailed data about the economic costs of care rather than a lack of awareness that economic costs exist for these caregivers. Some exploration of these caregivers' costs has occurred (see Clark, 1994 for an example of family costs for care of persons with severe mental illness and substance abuse from a large mental health clinic in the U.S), but comprehensive examination of costs to family members and friends because of care for persons with mental illness in Canada is still in beginning stages (Health Canada, 2004).

Economic costs of mental illness for caregivers also remain "hidden" because stigmatization affects both persons who have a mental illness and their families (Health Canada, 2002d). Byrne (2001) describes psychiatric stigma as involving both internal and external aspects. "To be marked as 'mentally ill' carries internal (secrecy, lower self-esteem and shame) and external (social exclusion, prejudice and discrimination) costs…" (p. 281). Family members may be doubly stigmatized because of genetic links to someone with a mental illness (Berrettini, 2000). and because some blaming of families for "causing" mental illness still occurs despite changes in theory about etiology (Levine & Lizenga, 2002; Milliken, 2001; Riebschleger, 2002). Families may find it easier to keep quiet about their costs of care rather than risk stigma for the care receiver and for themselves by calling attention to the mental illness. Johnson (2000) found evidence of some U.S. families spending their entire life savings to obtain private treatment for a family member with mental illness before turning to public sources as a last resort.

High costs to the public purse for expert care are being questioned for many areas of health care and disability services resulting in increased pressures for families and friends to provide more care in the community for many types of illnesses and disabilities (Gee, 2000; Kirby & LaBreton 2002; Kirk & Glendinning, 1998; Prince, 2003b; Rosenthal, 2000). At the same time, rising costs of living require employment of more family members for longer hours (Statistics Canada, 2002; Vanier Institute of the

Family, 2004). Family and friends are often considered to provide essentially "costless" care in the community based on their relationship with the person who needs care (Fast, Williamson, & Keating, 1999). An examination of what we know about family/friend caregiving raises serious questions about whether there actually are any savings to society through this strategy when the costs to caregivers and their potential need for future assistance are taken into consideration (Fast & Frederick, 1999). Concern has been expressed in Canada about continued sustainability of the care system (Canadian Mental Health Association, 2001; Hollander & Prince, 2002).

Caregiver costs and policy impacts are beginning to be explored for caregivers of seniors and for caregivers of people with particular illnesses and diseases. However, the costs for caregivers of persons with mental illness may not be the same. The potential severity, chronicity and episodic nature of many mental illnesses (First & Tasman, 2004) can result in periodic high costs for some caregivers and persistent lifelong care for others. These diseases often are drastically life-changing for the person experiencing them, their caregiver(s) and other family and friends. For many affected individuals, subtle changes in function and behaviour over time may precede diagnosis and treatment (Levine & Ligenza, 2002) and these can affect family caregiver costs long before the illness is identified. Unlike other types of illness, the reality of this type of illness is often questioned by family, friends and others, and denied by the person who has mental illness (Karp & Watts-Roy, 1999) which can result in little social, caregiving, or economic support for the person experiencing the illness or their caregiver(s).

The potential for long-term caring for persons who have mental illness may result in costs that are high, not only because of compounding of costs over time, but also because of age-related societal expectations of the caregivers. Caregiving can interfere with adult caregivers' employment during the years that they are expected to be working and accumulating resources to care for themselves in older age, resulting in significant work-related costs over a lifetime which may exacerbate other costs related to caregiving. There is little support available for able-bodied adults under 65 in Canada who become unable to work because of their life situation (LeBlanc & McMullin, 1997). Caring for adults with mental illness can also result in many out-of-pocket costs for expensive treatments and supportive services as well as costs in time spent in unpaid labour (Doornbos, 2001).

Characteristics of the diseases and the costs of caregiving may influence who provides care. As a nurse, I have noted the frequent listing of a friend, neighbour, or distant relative rather than a close family member as the "home" contact person for an adult with mental illness in hospital. My naïve question used to be, "Don't they have any family?" Recently, however, extended family experience has taught me that some caregivers can be "stretched and distressed to the limit," (Canadian Alliance on Mental Illness and Mental Health, 2000, p. 7) so that they experience too much cost to maintain a caregiver role (Karp & Watts-Roy, 1999). The costs may try even the closest relationships so that caregivers may feel like giving up on the person needing care (Jones, 1997). Little is known about how much care is being done by which family members and friends in Canada and what costs they are incurring to give that care. Even less is known about how public policies in Canada may affect costs for caregivers in different relationships with the person who has mental illness.

Although we know that mental illness has many costs, we are most knowledgeable about psychological, physical and social impacts for the person with the illness and to their caregiver(s). Shifting care to the community has resulted in many economic costs to caregivers that have not been explored. Stigma, denial and oversight in calculations obscure our knowledge about these costs. Economic costs can impact the quality of life of the caregivers now and in the future. Public policy often addresses economic issues. Analysis of how public policy addresses these economic costs in Canada, however, is lacking. Further information about these caregivers and their costs is needed to inform policy.

Purpose

The purpose of this study was to identify the kinds of economic costs that are experienced by family and friend caregivers of persons with mental illness and to evaluate how current public policy in Canada affects these costs.

CHAPTER 2: LITERATURE REVIEW

In the literature on costs of caregiving, there are three themes of interest for examining economic costs of family and friend caregivers and policy impacts on these caregivers' costs. Theme one is that caregiving can result in a variety of costs. Theme two is that costs differ for different types of caregivers. Theme three is that public programs may or may not reduce caregivers' costs.

1. Caregiving Can Result in a Variety of Costs

For over 25 years, studies about caring for persons with mental illness have been conducted primarily from a burden/stress/coping perspective with a predominant focus on social and health impacts of caregiving (Fine, 2005). Economic costs are mentioned as financial strain or economic stressors that contribute to the overall stress of the caregivers, but with little examination of how these costs may be differentially incurred by caregivers (Arksey, 2003; Ohaeri, 2003; Provencher, Perreault, St-Onge, & Rousseau, 2003). Examination of the financial hardships of these caregivers is still in early stages (Madianos et al., 2004).

The absence of clear and consistent definitions of costs for this population of caregivers prompted questions about how to begin to tease apart the evidence of caregiver costs for other populations of caregivers and what would apply to persons caring for a family member or friend with mental illness. A taxonomy of costs of care to older adults developed by Fast, Keating, Oakes and Williamson (1997) based on review of the caregiver literature and consultation with experts in the field of family/friend care to frail older adults provided a starting point to organize the literature on caregivers of persons with mental illness. Although many costs of care may be similar for caregivers of persons with a variety of illnesses and disabilities, it is acknowledged that costs may differ between these populations. For example, older adults may have accumulated more economic and social resources throughout their lives that can help with caregiving costs. Seniors also are more likely to have time-limited need for care. In this review of literature, information from other caregiving populations will be introduced to raise questions about caregiver costs for which there is little known about caregivers of persons with mental illness.

The taxonomy of costs of care developed by Fast et al. (1997) delineated two main categories of costs: non-economic and economic. Non-economic costs were defined as decreases in quality of life in physical, social and emotional realms. Economic costs were defined as money or money-equivalents that are expended or lost because of family/friend caregiving through employment-related consequences, out-of-pocket expenditures and unpaid labour. Both non-economic and economic costs are described in the literature about caregivers of persons with mental illness. However, the focus has primarily been on non-economic costs, especially psychological (e.g., Cannuscio et al., 2002) and social costs (e.g., Colantonio, Cohen, & Pon, 2001; Hepburn, Tornatore, Center, & Ostwald, 2001; Jeon, 2003; Ohaeri, 2003). Although both non-economic and economic costs have important impacts on the lives of caregivers of persons with mental illness, economic costs can markedly affect the standard of living of the caregivers both in the present and the future, can affect the availability of caregivers for those who need care and can be more readily addressed by public programs than can non-economic costs (Fast, Eales, & Keating, 2000).

Employment-Related Costs

Caregiving can result in marked employment-related costs (Carmichael & Charles, 1998; Fast et al., 2000; Mature Market Institute, 1999). Disruption of employment because of caring for a family member or friend can result in loss of present and future income, decreases in productivity, lost current and future employment-related benefits and lost opportunities for advancement (Fast et al., 1997).

The nature, course and treatment of many mental illnesses may result in high employment-related caregiver costs. In Canada, 59% of primary caregivers of persons with mental illness are in the labour force with 32% of caregivers employed full time (Health Canada 2004). However, a larger percentage of caregivers for persons with mental illness are not employed than is seen in the general population (40% of the caregivers compared to 32% of the general population) (Health Canada, 2004). This suggests that more caregivers of persons with mental illness incur employment-related costs than do people who are not caregivers to those with mental illness.

For those who remain employed, caregiving disrupts employment and often requires adjustments in order to maintain both work and caregiving. Eighty-four percent of employed family and friend caregivers of a person with mental illness experienced some interference with their employment that was directly related to their caregiving and 18% of caregivers chose the description of "significant" job interference due to caregiving (Health Canada, 2004). A process of "juggling" care and work responsibilities has been described for persons giving care to older adults (Guberman & Maheu, 1999; Mature Market Institute, 1999). This has been noted to result in adjustments at work such as changes in hours worked, absences, longer breaks and use of vacation time which may be associated with costs to caregivers (Fast et al., 2000; Gignac, Kelloway, & Gottlieb, 1996). Similar results have been found for persons caring for cancer patients (Grunfeld et al., 2004), terminally ill persons (Passik & Kirsch, 2005) and persons with dementia (Suh, Knapp, & Kang, 2002). Ensuring that family and friends with mental illness obtain and maintain treatment can be particularly disruptive to caregiver employment because this may require frequent visits to agencies and health care professionals for treatment, rehabilitation, training and socialization activities at times that may conflict with work schedules (Chaffey & Fossey, 2004; Milliken, 2001).

For some, caregiving may totally preclude employment so that the caregivers leave employment by quitting or retiring early (Szinovacz & Davey, 2005), or never entering the workforce. Six percent of Canadian caregivers to persons with mental illness have left employment either by quitting or retiring early in order to provide care (Health Canada, 2004). Constant vigilance because of illness-related problematic behaviours coupled with limited awareness of consequences of actions of some persons with mental illness interfere with employment of their caregivers (Maes, Broekman, Došen, & Nauts, 2003). Caregivers of persons with severe, lifelong mental disabilities diagnosed in infancy or early childhood may never even enter the workforce (Sawatzky & Fowler-Kerry, 2003).

If a caregiver cannot sustain employment and caregiving (Gignac et al., 1996; Wuest, 2000) and they leave employment, they can lose current and future income and benefits such as extended medical insurance, prescription coverage, life insurance, disability insurance (Evandrou & Glaser, 2003) or educational and experiential opportunities that might improve present and future employment prospects (Kneipp, Castleman, & Gailor, 2004). Furthermore, the value of their skills and experience may decrease over time while they are not employed, lowering their likelihood of re-employment and the wage level that they could achieve if re-employed (Carmichael & Charles, 1998). Reduced contributions to pension plans (Carmichael & Charles, 1998; Evandrou & Glaser, 2003) and retirement saving can have serious long-term economic costs.

Because of the episodic nature of mental illness, caregiving may require constant vigilance and flexibility to act when the need for care arises (van Meijel, van der Gaag, Sylvain, & Grypdonck, 2004). These caregivers may be less available for either caregiving or employment responsibilities (Gignac, Kelloway, & Gottlieb, 1996) decreasing their productivity in both realms and decreasing their desirability as employees and their potential for advancement (Appelbaum, Bailey, Berg, & Kalleberg, 2002; Guberman & Maheu, 1999). Instead of working overtime, being available on short notice, attending functions outside of work hours, or committing time to continuing education, caregivers for persons with mental illness may need to leave with little or no advance notice for unpredictable periods of time when crises or relapses occur (Hewitt & Birchwood, 2002; van Meijel et al., 2004). Loss of work time and loss of advancement opportunities can cost the caregiver present and future income and employment-related benefits offered through job advancement.

Little is known about lifetime employment-related costs for caring for someone with mental illness. A U. S. study of people caring for seniors at least 8 hours per week over an average 5 to 7 year period, estimated employment-related lifetime economic costs in current and future income to equal an average of the equivalent of $1,034,117 CDN per caregiver (Mature Market Institute, 1999). This calculation included only estimated losses of income, government pension benefits and private pension benefits.

The length of time that may be involved in caring for many persons with mental illness may well result in higher lifetime employment-related costs. Sixty-nine percent of caregivers for persons with mental illness in Canada have been giving care for over three years and 30% of them have been giving care for 11 years or more (Health Canada, 2004). Longer term caregiving may have cumulative employment-related costs as the caregivers use up their options for making work adaptations because of caring.

Out-of-pocket Costs

Not only are family/friend caregivers likely to incur high employment-related costs, many pay considerable out-of-pocket expenses because of caregiving. Fast et al., (1999) define this type of costs as, "expenditures that would not have been made had informal care not been provided" (p. 304). The three categories of out-of-pocket caregiver expenditures that Fast et al (1999) described are very relevant to caregivers of persons with mental illness. They involve paying for goods for the care receiver, services for the care receiver and purchasing time for the caregivers themselves in order to give care. An additional, and potentially unique, out-of-pocket cost category that seems evident in the literature about caregivers of persons with mental illness involves paying costs of decisions and actions of the person who has mental illness (Clark, 2001; Milliken & Rodney, 2003).

Out-of-pocket expenditures are not unusual for family and friend caregivers but frequency, magnitude and particular reasons for the costs may differ for this group of caregivers from those that are to likely to be incurred with other types of illnesses. Health Canada (2002c) found that 44% of family caregivers for persons with various types of illnesses and disabilities incurred out-of-pocket caregiver costs, but a much larger proportion (58%) of caregivers for persons with mental illness incurred out-of-pocket costs (Health Canada, 2004).

Expenditures by caregivers for goods needed to give care may occur because the care receiver cannot afford to meet their own needs (Wilton, 2004). Caregivers purchase goods and services or transfer money to the person who has mental illness, even to the point of threats to their own health or income security (Altman, Cooper, & Cunningham

1999; Wilton, 2004). These purchases and money transfers may be particularly important for the well-being of the care receivers because higher proportions of those with a mental illness in Canada live in poverty than those without (Wilton, 2004). Symptoms of mental illness, effects of illness on educational and employment preparation, side effects of treatment medications and stigmatization can challenge the ability of persons with mental illness to obtain and maintain adequate employment (Cook, 2006), a condition that increases their risk of poverty throughout life and increases their need for economic assistance from others (Baron & Salzer, 2002). According to the Canadian Mental Health Association (2001), "most people with serious mental illness [in Canada] are not employed" (p. 20).

The most common out-of-pocket expenditures for goods are for prescription medications (56%) and non-prescription medications (51%) (Health Canada, 2004). Prescription medications for mental illness treatment can be very expensive and often are necessary throughout life (Health Canada, 2002d). For example, olanzapine, a commonly used medication for treating schizophrenia, costs approximately $130 per month at an average dose level (personal communication, Chris Graham, pharmacist, Shopper's Drug Mart, May 27, 2005). Often combinations of several prescription and non-prescription medications are required, some to treat the illness and some to counteract side effects of the treatment medications (Lehne, 2007).

The most frequent out-of-pocket costs for services include transportation, homemaking and professional services. Seventy-six percent of caregivers incur expenses for transportation (Health Canada, 2004). Poverty may make a vehicle unaffordable for the care receiver (Wilton, 2004) and disease symptoms (Townsend, 2006) and/or medication side effects (Lehne, 2007) may interfere with driving for persons with some types of mental illness. Costs for transportation may vary depending on local availability and prices of public transportation. Forty-three percent of caregivers surveyed by (Health Canada, 2004) purchased homemaking services such as housekeeping for the person who has mental illness. Thirty-three percent noted costs for professional services such as psychologist or counseling appointments for their family member or friend (Health Canada, 2004). Some employment benefit plans pay for such visits, but for 79% of persons with mental illness in Canada the costs of psychologist visits are a private expense (Canadian Psychological Association, 2001, p. 8).

Caregivers also purchase help from others, either to supplement their care or to free up time so that they can fit caregiving within their lives (Fast et al., 2000; Pedlar & Hutchinson, 2000). Hiring someone to stay with a person who has mental illness may cost more than for persons with some other diseases or disabilities because it can require particular skills and experience, especially if the person is an adult with mental illness who exhibits any violent behaviour (Solomon, Cavanaugh, & Gelles 2005). It may be easier and less expensive for the caregivers to hire someone to replace themselves for some of their other responsibilities such as child care or housework in order to free up time (Fast et al., 2000). Smaller proportions of those who had out-of-pocket costs incurred expense by hiring persons more specifically prepared for caring for an individual with mental illness: 11% for a personal care worker and 10% for nursing services (Health Canada, 2004). Amounts of out-of-pocket expenses for supplementary help are correlated with the economic status of the caregivers (Health Canada, 2004). Those who can pay, often do while those who cannot pay may have little other recourse than to do the work themselves. Continuing to give care without assistance may lead to eventual increased public costs if psychological (Prigerson, 2003) and/or physical (Patterson & Grant, 2003; Vitaliano, Zhang, & Scanlan, 2003) damage to the caregiver occurs because of caregiving.

Expenses related to paying because of decisions and actions of the person who has mental illness may be a cost of caregiving that is unique to caregivers of these individuals. Descriptions in the literature include such items as providing bail and legal fees (e.g., Clark, 2001; Clark et al., 1999; Milliken, 2001), paying for long distance telephone calls, damages and relocation fees in case of eviction from housing and for financing searches to find and return a runaway adult with mental illness (Milliken & Northcott, 2003). For some persons, rapidly incurring high levels of debt is a well-documented symptom of mania, a particular manifestation of mental illness (American Psychiatric Association, 2002; Townsend, 2006). The nature of some mental illnesses may result in these individuals outwardly appearing perfectly healthy and yet having their cognition affected by their illness. With some mental illnesses, cognition is only sometimes affected (Townsend, 2006).

Unpaid Labour Costs

Waring (1999) described unpaid caring labour as a productive activity that is economically valuable in its own right but often is hidden. She notes that "if you are invisible as a producer in a nation's economy, you are invisible in the distribution of benefits" (p. 35). Much of the care that is required for persons who have mental illness is invisible because household work is often involved, but it is extra to expected family household work for persons unaffected by mental illness. Clark (2001) described many more hours being spent in money management, transportation and shopping by caregivers for adults with mental illness than on behalf of adults without mental illness.

Time spent in care is an opportunity cost for the caregiver because it is unavailable for other uses. Not having enough time can profoundly affect the quality of life of the caregiver with physical (Vitaliano et al., 2003), psychological and social as well as economic costs (Patterson & Grant, 2003; Saunders, 2003). The time not only is unavailable for employment, which can result in employment-related costs, it is unavailable for other uses that are of value to individuals as well. Colman (1998) defines "time poverty" as "time below the minimum necessary for basic household production" (p. 35). Time poverty may result when more time is spent on unpaid labour than can be spared without damage to the individual and their household's activity (Fast & Frederick, 1996). Caregiving over a long time period may compound the costs of unpaid labour as activities that are left undone accumulate and may become more time consuming to accomplish later.

Care for persons with mental illnesses may involve high unpaid labour costs because of needs for continued vigilance and repeated timely interventions. Periodic exacerbation of some mental illness can occur despite careful control of medication and milieu (Hewitt & Birchwood, 2002; van Meijel et al., 2004). Side effects of medications are frequent and some are life-threatening. Monitoring of diet, health status and even fluid balance is necessary with some psychiatric medications (Lehne, 2007). Insight and cognition may be affected by the illness. Some mental illnesses may result in lack of realization by the affected person that they need treatment (Hewitt & Birchwood, 2002). There may be no choice for the caregiver of when to give unpaid labour if, for instance, paranoia or delusional ideas could contribute to missing treatments or even to suicide (Milliken & Rodney, 2003). Some tasks must be repeated, often for years, because the symptoms of some mental illnesses mediate against empowerment and development of independence in the individual who experiences them (Cook & Jonikas, 2002). The requirement to be "on call" for much of the time to spot sometimes subtle changes can be very tiring and can impede other activities of life (Petronio, Sargent, Andea, Reganis, & Cichocki, 2004). A multi-country European study of 287 care dyads found that over 48% of caregivers spent over 32 hours per week in contact with a person who has schizophrenia even if they were not the primary caregivers (Meijer et al., 2004).

Health Canada (2004) found that the following unpaid labour tasks were performed either daily or occasionally by many of the caregivers of persons with mental illness: "providing companionship, providing emotional support during a crisis, monitoring symptoms, providing or monitoring medications, paying bills, advocating for the person to receive help, arranging and coordinating services and appointments, assisting with personal grooming and accompanying them to appointments" (p. 28). Although some tasks may not be as frequent, time and energy expended may influence caregivers' quality of life. For instance, dealing with law enforcement personnel related to substance abuse or other problematic behaviours associated with some kinds of mental illness may contribute to the hours spent in unpaid care (Clark et al., 1999)

Although the amount of time spent on tasks related to care of persons with mental illness in Canada is not known, we do know that other Canadian populations of caregivers contribute substantial amounts of unpaid labour through their caregiving (e.g., Fast & Frederick, 1999; Michelson & Tepperman, 2003; Statistics Canada, 1999). Based on replacement costs using data from the 1996 General Social Survey, the unpaid labour alone for giving care to older adults in Canada has been valued at over $5 billion per year (equivalent to approximately 275,509 caregivers working full time to replace the caregivers with paid employees) (Statistics Canada, 2003).

2. Costs Differ for Different Types of Caregivers

Costs Differ by Gender

The gendered nature of caring is one of the most common sub-themes within the costs of caregiving literature. About 2.1% of the adult Canadian population, approximately half a million adults, are primary family and friend caregivers for persons who have one (or more) of the five major categories of mental illnesses (mood disorders, schizophrenia; anxiety disorders, personality disorders and eating disorders) (Health Canada, 2004). Seventy percent of these caregivers are women.

Families may choose a lower-income family member to care in an attempt to reduce the family's overall economic costs of caregiving (Carmichael & Charles, 2003; Fast & Frederick, 1996). This decision often leads to women being caregivers because their wages are lower than men's (Myles, 2000). Results of gender stratification in care costs over a long time are of particular concern (Zimmerman, Mitchell, Wister, & Gutman, 2000) because women already tend to spend more time away from employment than men due to family responsibilities (Blau, Ferber & Winkler, 1998; Duxbury & Higgins, 2003), especially because of childbearing and childrearing activities (Evandrou & Glaser, 2003; Gray and Chapman, 2001). This discrepancy, combined with lower overall wages for women, results in less pension investment and benefits overall for women (Evandrou & Glaser, 2003)--a population that lives longer in old age, with more severe disability and higher poverty rates than men (DesMeules, Turner, & Cho, 2003; Myles, 2000; Statistics Canada, 2004b).

Women who are employed experience high employment-related costs from "repatterning" their work, to make caregiving fit within their lives (Wuest, 2000). Such work accommodations frequently result in decisions such as taking lower paying, often part-time, jobs with little chance for advancement because they fit their available hours, a choice that can result in losses of current and future income and employment-related benefits as well as serious pension penalties over a lifetime (Evandrou & Glaser, 2003). Chaffey and Fossey (2004) found that women's alteration of their own occupational involvement for caregiving affected their advancement more frequently than did men's.

Arber and Ginn (1995) found in their study of 2700 family/friend caregivers in the UK that employment did not reduce the availability of women for caring for seniors, resulting in women having high totals of unpaid labour as well as paid work. Unpaid labour costs may also be higher for women caring for persons with mental illness because they may be more likely to be the sole caregivers. In a U.S. study of 180 caregivers of persons with serious mental illness, Johnson (2000) found that, although other family members may be available to help if asked, generally one female caregiver provides the bulk of the care with other family members tending not to offer help for fear of becoming the primary caregiver.

Extensive review of the literature reveals very little about economic caregiving costs for male caregivers of persons with mental illness. Kramer and Kipnis (1995) attribute a similar lack of information about male caregivers for older adults to a concentration of research on the types of caregiving tasks that women are most likely to do and question whether our knowledge may, therefore, be biased against men. Mays and Lund (1999), however, through their small U.S. qualitative study of 10 men caring for a family member with mental illness, found that those men experienced all three categories of costs.

Men caregivers for persons with mental illness are more often employed full time than are women caregivers (Health Canada, 2004). If they miss work because of care, men are likely to incur higher employment-related costs hour for hour due to loss of present wages because of the differential in men's and women's wages (Carmichael & Charles, 2003). However, men do not tend to quit work or greatly reduce work repeatedly over their lifetime for childbearing, childrearing and caring for more than one person concurrently (Spillman & Pezzin, 2000) as do women (Evandrou & Glaser, 2003). Duration and amount of employment tends to vary according to gender, however, with men caregivers working more and longer at paid employment than women (Chaffey & Fossey, 2004). In fact, Dentinger and Clarkberg (2002) found in their U.S. study of 763 pension-eligible caregivers for seniors and persons with a disability, that men caregivers tended to continue working longer and women caregivers tended to retire sooner because of caregiving, a condition that is likely to result in fewer overall employment-related costs for men than women in lifetime wages and benefits.

There is some evidence that the ways that men and women make accommodations in their employment to give care may differ. The Mature Market Institute (2003) found that men caregivers for older adults tended to refuse overtime less often than women, to take unpaid leaves less often than women and to modify their work travel much more often than women. These findings, however, should be interpreted with caution because only employees of Fortune 500 companies were contacted and the response rate was only 5%. Some of men's accommodations to caregiving, however, are quite different than women's. Men have been noted to delegate tasks more frequently (often to their spouse) (Gerstel, 2000) and to use formal services more often than women (Coe & Neufeld, 1999). Use of formal services that involve cost may increase men's out-of-pocket costs, while women who are doing the work they have been delegated and using less formal services have higher unpaid labour costs.

It is possible that gendered division of caregiving tasks might also lead to differences in caregiver costs because of differences in time required for some tasks. Gendering of tasks along traditional gender role lines with men doing yard work and financial management and women doing cooking and bathing has been described by many authors (see for example, Campbell & Martin-Matthews, 2003). Some have described these as "managerial" roles for men and "hands on" roles for women (Raschick, & Ingersoll-Dayton, 2004). However, there are indications that there may be little difference in these roles among employed caregivers. For instance, Kramer and Kipnis (1995) found no significant differences in the amount of managerial care performed by men and women in their study of 512 nonspousal caregivers for seniors. Neal, Ingersoll-Dayton and Starrels (1997) in their U.S study of 2144 employed caregivers to older adults included spouses, other relatives and friends and found no significant gender differences in managerial versus more personal care roles when other factors known to contribute to caregiver burden were statistically controlled. Employment status may not be a factor in gendering of tasks among those who give care to persons with mental illness. All tasks were found to be equally likely to be done by either gender in caring for persons with mental illness (Health Canada, 2004).

Costs Differ by Relationship

Differences in experiences of caregivers in different relationships with the person receiving care is the second most common sub-theme in this literature. People become caregivers for many reasons, but perceived family obligation is a frequent factor noted in the literature (e.g., Piercy, 1998). Eighty-six percent of caregivers for persons who have mental illness in Canada acknowledged that their motivation for caring was based on a belief that "it is a family responsibility" (Health Canada, 2004, p. 26).

Although many family and friend relationships are represented among the caregivers of persons with mental illness, parents form the largest proportion (30%), most of whom (91%) are caring for their adult children (Health Canada, 2004). In a Canadian qualitative study of parents of adults with mental illness (Milliken and Northcott, 2003) parents of adults with schizophrenia tended to perceive no choice about whether to care, because "no one else takes a perpetual interest in the child's well-being" (p. 110).

Parents are more likely than spouses or other caregivers to be caring for a person who has a mental illness that occurs early in life, such as obsessive compulsive disorder (Hasse, 2002) or schizophrenia (Health Canada, 2004). Such illnesses may result in very high lifetime caregiver costs because of compounding of costs over time and because they may interfere with education, employment and development of independence of the person who has mental illness (Cook, Cohler, Pickett, & Beeler, 1997). Compounding of employment-related caregiver costs over a long time, perhaps even a lifetime, makes caregiving especially costly through losses of present and future employment income, benefits and advancement. Parents are noted to have work disturbances for care (Milliken & Northcott, 2003). Lifelong co-residence with parents that frequently occurs with some types of mental illness (Botsford & Rule, 2004; Horwitz, Reinhard, & Howell-White, 1996) may increase many types of out-of-pocket costs for parents, such as accommodation-related expenses and food. Parents "fill in the gap for both necessities and small luxuries" (Milliken, 2001, p. 156) for adult children who have schizophrenia including psychotherapy, dental care and medications not covered by the provincial medical plan. Transportation costs were also noted to be higher for parents. Clark (1994) described parents as spending 500% more on transportation for adult children with mental illness and substance abuse as on adult children without these problems.

Twenty-four percent of the caregivers for persons with mental illness are spouses (Health Canada, 2004). Spousal relationships with persons who have mental illness may involve costs of all types. Employment-related costs might be high especially if the spouse caregiver becomes the only wage earner due to illness of their partner. Dore & Romans (2001) found that spouses were much more likely than other family members to suffer decreased income because of their caregiving.

Caregiving may affect the caregiver's work by disrupting sleep (Willette-Murphy, Todero, & Yeaworth, 2006). The behaviours of a spouse who has mental illness and the need for vigilance may disrupt sleep even more than for other relatives, due to the intimacy of the spousal relationship. Out-of-pocket spending may be high because of paying for medications, treatments and other expenses. Caregiving spouses may also incur costs because of decisions and actions of the person who has mental illness that are unique to a spousal relationship because of joint responsibility for debts incurred by the spouse who has mental illness (e.g., see Immigration Quebec, 2005). Spouses may also be unable to access help that is otherwise available to people in other relationships (Mannion, 1996) because care of spouses is assumed to be an obligation (Boyd, 2000).

Almost half (47%) of all caregivers for persons who have mental illness are other family members and friends (Health Canada, 2004): their children (15%), relatives such as siblings, grandparents and others (18%) and unrelated persons (14%). Greenberg, Seltzer, Orsmond, and Krauss (1999) found that one-third of the siblings of adults with mental illness in their US study expected that they would become the primary caregiver at some future time, generally after their parents could no longer provide care. The economic costs involved with sibling care, however, are not well known (Jones, 1997).

Costs Differ by Relationship and Gender

There is some evidence of potential differences in costs because of the interaction of gender of the caregiver and their relationship to the care receiver (e.g., Neal et al., 1997). The interaction between gender of the caregiver and the caregiver's relationship to the care receiver may result in different caregiving obligations (McDaniel, 2001) and resulting costs (Campbell & Martin-Matthews, 2003). For example, fathers and mothers are impacted differently by caring for their adult child with schizophrenia (Milliken, 2001). This may not be just a comparison according to gender, however, because different roles are played out based on the interaction between gender and relationship. Silverstein, Buxbaum, Tuttle, Knudson-Martin, & Huenergardt (2006) contend that both people's gender and their relationship affect their actions with others because of obligations, roles, norms, power and the context in which they are embedded. Pickett-Schenk (2003) argues that in caring for persons with mental illness, mothers, daughters and sisters have different caregiving demands and costs than each other as well as differences from fathers, sons and brothers.

Often the research looks at only one relationship or compares only corresponding relationships (such as father versus mother caregiver and male versus female spouse caregiver) so it is difficult to know how both gender and relationship may influence the costs of caregiving across the spectrum of caregivers. For example, Neal and associates (1997) found that female spouses spend 300% more time on care than do male spouses. However, we do not know whether persons in other relationships by gender, for instance, sons or mothers, have different caregiving time costs. Differences can be obscured when only caregiver gender or caregiver relationship to the care receiver is considered when investigating caregiver costs (Grant, 2000). For instance, differences in male and female costs due to delegation of tasks to women by men (Gerstel 2000) or differences in costs resulting from greater use of formal services by men (Coe & Neufeld, 1999) may not show if we look at only relationships, such as parents, siblings, etc. Likewise, looking only at gender differences in cost may obscure the differences in cost incurred by particular relationships. Examination of caregiving costs by both gender of the caregiver and relationship with the care receiver across the spectrum of caregivers would more finely distinguish which group(s) of caregivers experience high costs. However, this was not found in the literature.

3. Public Programs May or May Not Reduce Caregivers' Costs

There is a growing discourse in Canada about the extent of caregiver economic costs and how public policy may differentially affect these costs (Prince, 2003a). Costs of caring for persons with an often chronic, episodically acute and very severe illness may be amenable to public policy intervention but this is not always happening, as is evidenced by recent caregiver testimony included in government reports such as *Out of the shadows at last* (Government of Canada, 2006). For example, one mother caregiver included this testimony, "I will speak of my own situation. I have nothing. I will remain in poverty for the rest of my life. […] I will never own a home, a decent car. I may never even be able to hold down a decent job because of my son's disability" (Government of Canada, 2006, p.30). Describing lack of programs that pay treatment costs, another anonymous person included this statement, "I have no access to any treatment to help him be a productive member of society unless I fund all treatment myself. However, if I just choose to put him on drugs and let him sit in the corner, the province will willingly provide [note: province is not stated]" (Government of Canada, 2006, p.30). Discussion papers also link loss of wages and even loss of jobs to lack of programs to reduce costs to caregivers (Prince 2003b) as well as caregiver costs incurred because of gaps in disability policy (Prince, 2004).

Previous policy impact analyses for two other populations of caregivers in Canada have shown differential benefit from public programs that could reduce caregiver costs. For example, analysis of policy impacts for caregivers of frail seniors in Canada showed benefit for some caregivers and not for others primarily because the eligibility criteria and user fees ruled out many who give care and incur large costs (Fast et al., 2000). Keating, Eales and Fast (2001) found that for programs that were in place to assist with the care of Canadian veterans, some family or friend caregivers who incurred costs benefited from the programs while others did not. The main eligibility criterion that qualified clients for assistance from these programs was veteran status. It was the veteran who was eligible for benefits, although the caregivers' costs might be reduced indirectly by benefits the veteran received. Veterans Affairs Canada offered a caregiver allowance program to assist in the costs of care for veterans, but this was paid to the veteran who could choose to use it for purposes other than paying a caregiver (Keating et al., 2001).

Whether public programs in Canada that could reduce costs for family and friend caregivers do reduce their costs is largely unknown, or at least undocumented in research papers, although discussion of this topic concerning particular programs occurs frequently on the websites of mental health, disability and caregiver advocacy groups. A systematic analysis of the economic impacts of public programs that could reduce the costs of caregivers who have high costs related to caring for someone with mental illness was not found in the literature, but this could be very useful for identifying strategies to avoid long-term economic damage to caregivers that could require much societal assistance in old age.

Conclusion

The literature provides evidence of a variety of costs for caregivers of persons with mental illness, many of which are similar to other types of caregiving. Some costs, are unique, arising from characteristics of mental illness, behaviours resulting from these illnesses and their treatments, and many of these costs are hidden. One notable difference in kinds of costs to caregivers of adults with mental illness involved dealing with the outcomes of actions that are affected by mental illness.

Employment costs are likely to be incurred because of employment adjustments related to ongoing needs for caregiver assistance and to the necessity for prompt episodic caregiver response when crises arise. Out-of-pocket costs may be high because of providing transportation, medication and other treatment costs, as well as contributions of other goods and services to the care receiver due to their disability and financial needs. Both out-of-pocket costs for purchasing of time by the caregiver and the unpaid labour costs are likely to be high because of ongoing needs for contributions of effort, energy, thought and time over many years.

The literature provides evidence that caregiver costs may not be evenly distributed and that costs vary by gender and relationship. Women are more likely than men to incur employment-related, out-of-pocket and unpaid labour costs of caregiving during their lifetimes, particularly because of repeated caregiving throughout life. The associated compounding of loss of income and benefits may result in high overall cost that can affect the caregivers' quality of life. Relationship may influence obligation to care and result in caregiver costs especially for parents, spouses and siblings of persons with mental illness. Interaction of gender and relationship may result in differences in costs of caregiving because of differences in roles and obligations that are based on both gender and relationship, but this has not been explored well for caregivers of persons with mental illness.

Public programs may reduce high caregiver costs, but whether they do and by how much has not been explored systematically in Canada.

Research Questions

1. Does incurring of high costs vary by gender and relationship for primary caregivers of community-dwelling adults with mental illness in Canada?
2. Do current public programs in Canada reduce economic costs incurred by caregivers who experience high costs?

CHAPTER 3: METHODS

Data to address Research Question 1 and to provide information for creating caregiver profiles in order to answer Research Question 2 were drawn from a national telephone survey of 343 main unpaid caregivers of a person of any age with mental illness in the community in Canada[1] (see APPENDIX A for questionnaire) This study is unique in its inclusion of a number of caregiving costs of family/friend caregivers of persons with mental illness in the community in Canada.

Source of Quantitative Data

Survey Sampling Method, Structure and Criteria

Contacts were made using an automated telephone dialing program to assure equal chance of contacting any household with a telephone in Canada. Up to eight callbacks were used in cases of no answer. Those who currently (or had within the last year) provided unpaid care in the community to a family member, friend or neighbour, who had a mental illness, (excluding dementias, addictions, developmental delays and acquired brain injury as the primary disorder) were eligible. Survey participants were invited to refer other interested caregivers for the study and this may be a limitation. Whether those who might have been referred differ in any systematic way from those who were contacted randomly is not known.

The survey included questions reflective of both the recent caregiving literature and literature on care to persons with mental illness. Caregiving impacts on employment, out-of-pocket expenses, unpaid labour for care tasks, as well as coping with caregiving were queried. Questions on types of informal care tasks were reflective of tasks commonly described in the mental illness literature.

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[1] Permission was granted from Health Canada for secondary analysis of these data (see Appendix A). The opinions expressed herein do not necessarily reflect those of Health Canada.

Use of the Data for the Present Study

Data that were available did provide some information to assist in describing the caregivers, the care receivers, and the caring costs for the present study. However, some data necessary to make definitive conclusions were not available in the survey. Available caregiver data included: gender; age range; other persons for whom caregiver gives care (as well as their gender, age range and relationship to the caregiver); presence and number of others living in the household (including number of children under 16); employment status; whether change or disruption of employment had occurred; modifications that caregivers would like; amount of out-of-pocket expenditures and what was purchased; types of caregiving tasks performed and frequency of performance; reasons for giving care (or no longer giving care, if applicable); formal services used, whether these were purchased by the caregiver, evaluation of usefulness, and other help desired by caregiver; language of interview; whether of Aboriginal descent, and whether living on or off reserve. For the care receiver, data included gender, age range, disorder(s) and length of illness. For the dyad, data included duration of care, location of care, relationship. Data for caregiver and care receiver income were not available in the survey, two items which would be likely to leave eligibility decisions uncertain if they are based on income of either party. Steps taken to compensate for this are discussed in the section on creation of the profiles.

In order to address the research questions, data from the following domains of questions were used: type of recipient/reasons for care, caregiving tasks performed, employment status and impacts. In order to focus on impacts of caring for adults, a subsample of those caring for adults age 18 yrs. and over (n=303) was used. All caregivers for minors who have mental illness were excluded because costs of caring for a minor and programs that could address these costs may differ from those for caregivers for adults with mental illness. Five caregivers did not specify their relationship and, therefore, were omitted from calculations which brought the sample size to 298. Cases for which other required data were missing were also omitted from calculations bringing the n for some cost categories to less than 298.

Operationalizing Variables

Caregiver gender and relationship to care receiver: dummy variables were created for each gender for the following relationships: spouses, parents, parents-in-law, stepparents, children, children-in-law, stepchildren, grandchildren, great-grandchildren, siblings, siblings-in-law, nephews/nieces, uncles/aunts, cousins, grandparents and unrelated persons. The survey sample was found to contain no fathers-in-law, stepfathers, grandsons, great-granddaughters, stepchildren or cousins among the primary caregivers (see Appendix B, Table B1).

For costs of care, data related to five care costs were available in the survey. Five dummy variables were created to distinguish high cost from not high cost in these areas (see Appendix B, Table B2).

Employment-related costs: Two measures of employment-related costs were defined as 'high' costs: forgoing labour by 'quitting or retiring early for caregiving' and job disruption described by the caregivers as 'significant.' The potential for lifelong changes in quality of life for the caregiver due to loss of present and future income and employment benefits if caregivers cease to work in order to give care is well documented in the literature. The caregiver was considered to be their own best judge of their level of employment-related disruption resulting from caregiving. Caregivers chose from a scale of 'significant,' 'some,' 'minor,' or 'none.'

Out-of-pocket costs: Two measures of out-of-pocket costs available from the survey were defined to be high: 'more than $400 per month in out-of-pocket costs' and financial difficulty described by the caregiver as 'significant.' It can be debated whether over $400 per month is a high cost, as much is relative to the income of the caregiver. However, the care receivers were all adults for whom financial support by family or friends is not generally the norm in our culture (unless they are a spouse). Over $400 includes the two highest levels of spending designated in the survey. The caregiver was considered their own best judge of their level of financial difficulties resulting from caregiving. Caregivers chose from a scale of 'significant,' 'some,' 'few,' or 'none.'

Costs of unpaid labour: no time use data were available in the survey. However, one measure of unpaid labour was available, an activity index. The survey designers created this by summing the results of answers weighted to reflect 'daily basis,' 'occasional basis,' 'rarely,' and 'never' for the frequencies of performance of 10 common tasks of care described in the literature. The two highest levels: active and very active were chosen to serve as a proxy for high unpaid labour cost.

Dummy variables were created for descriptors that could be clearly classified as either/or, otherwise ranges (such as age range) were used for the variable (see APPENDIX B Table B3 and B4) See Creating Caregiver Profiles for further detail.

Decisions Concerning Methods

Data limitations required a number of analytic decisions. Most survey were nominal, while ordinal data such as age and income often had categories that were uneven in size. Small sample size was small. Thus cell sizes for kinship relationship by gender were small, precluding multifactorial analyses. Thus patterns of costs for women and men caregivers of different relationships to the care receiver were illustrated by comparing the frequency of occurrence of different cost categories. This categorization allowed for comparison of the frequency of high costs for males and females in a variety of relationships. Chi Square or Fisher's Exact Test (as appropriate for the cell size) were used to test for significance.

Research Question 1

1. *Does incurring of high costs vary by gender and relationship for primary caregivers of community-dwelling adults with mental illness in Canada?*

In order to answer this question a five step process was undertaken:

1. testing whether statistically significant associations exist between relationships and the frequency of incurring high costs in each category using Chi Square or Fisher's Exact Test
2. determining whether gender alone makes a difference in incurring high costs by comparing the proportion of each gender that experienced high cost to their proportion of the caregiver sample

3. determining whether high costs were concentrated among caregivers related in specific ways to the care receiver by comparing the proportion of respondents in each relationship category reporting high costs to the proportion of the whole sample that they represented
4. identifying relationships that are at high risk of experiencing multiple high costs
5. identifying potential concurrent costs for high risk caregivers identified in step 4

In step 1, five sets of analyses were run, one for each type of cost, testing the null hypothesis that the distribution of a cost for any relationship group is not significantly different than the distribution for the rest of the sample. Presence of any significant associations of each type of cost with each relationship group was determined using Pearson's Chi-Square analysis when sample sizes were ≥30 or cell sizes were 5 or greater or Fisher's Exact Test when sample sizes were < 30 or cell sizes were < 5. Two-tailed measures of significance were determined, as it was assumed that the distribution of cost of any relationship group of caregivers could vary either negatively or positively from the distribution of cost of all other caregivers. These tests were chosen for power and robustness (Lyderson & Laake, 2003; Man, Wang, & Wang, 2000), suitability for two-tailed tests (Stefanescu, Berger, & Hershberger, 2005) and appropriateness for use with small numbers and nominal variables (Bower, 2003).

For step 2, since gender has been noted in the literature to influence caregiving costs with especially high costs described for women, the proportions of men and women who experienced each high cost was compared to the proportion of men and women in the caregiver sample. The null hypothesis, in this instance, would be that proportion of men and women in the sample should be the same as the proportion of men and women reporting high costs.

For step 3, since the Chi square and Fisher's Exact Test only test for association of high frequency of one high cost at a time and would not identify instances of multiple high costs that might be experienced concurrently by any relationship group, further comparison is necessary. Incurring multiple kinds of high cost could increase economic pressures. This analysis was done by comparing the proportion of each high cost that was borne by each relationship with their proportion of the total caregiving sample and looking across the costs for each relationship category to identify potential for multiple high costs. Using their proportion of the total caregiver sample for comparison takes into account differences in prevalence of relationships in the population. A null hypothesis, in this instance, would be that each group's representation in the caregiver sample should be the same as their representation among those with high cost if there is no difference according to relationship group.

Step 4. In order to focus on those who are most likely to have multiple high costs, within-group frequencies were also calculated for those relationship categories determined in Step 3 to have potential for multiple high costs. When the majority of members of a relationship group experienced a high cost, these cases were chosen for further analysis in Step 5. For the purposes of program impact analysis, this allowed a focus on those most likely to be experiencing high cost. Note: for this step, relationship groups of over 30 were analyzed in order to minimize the likelihood of extreme variability related to small numbers.

For step 5, frequencies of other high costs were generated for the caregivers identified in step 4 as well as the daughter caregivers (because this was shown to have a significant association found in step 1). These were identified as the 'high cost' caregivers for creation of example caregiver profiles for program impact analysis.

Research Question 2

2. *Do current public programs in Canada reduce economic costs incurred by caregivers who experience high costs?*

To answer question two, a program impact analysis was conducted for a set of federal, provincial and regional programs to determine whether they might reduce any of the three types of economic costs for caregivers who most frequently incur high costs of care. A five step process was used that was an adaptation of the methods employed by Fast et al, (2000).

1. Three high cost caregiver profiles were created based on data from research questions 1 and 2.
2. Policy domains that could contain programs to reduce caregiver costs were chosen.
3. Two areas of Canada were chosen for examination of federal, provincial and regional public programs that could reduce economic caregiver costs.
4. Documents related to the programs that could reduce caregiver costs both directly (through benefits to the caregiver) and indirectly (through benefits to the care receiver) were gathered and scanned for eligibility criteria, benefits, user fees and other associated costs of use and these programs were briefly described.
5. Analysis of program impacts was conducted considering types of caregiver costs, program benefits and costs, and regional differences in costs and benefits.

1. Creation of High Cost Caregiver Profiles

Caregiver profiles were necessary in order to be able to compare program criteria with some specific caregiver and care receiver details for determination of whether those who experience high costs would qualify for program benefits. Profiles were developed that were grounded in the descriptive data available from the Health Canada Survey (2004). Based on the findings of Research Questions 1, three caregiver types were identified as particularly at risk of incurring high costs:

- those relationships that were found to have significant statistical association with high cost
- and relationships in which over 50% of the relationship group in the survey experienced high cost.

These were chosen only from among the relationship groups with ≥ 30 members in order to minimize the impact of small sample sizes.

Any characteristics found in the literature review that could potentially raise caregiving costs or influence eligibility for benefits of programs were used (if available) to create the example 'high cost' caregiver profiles with the acknowledgement that little detail was available from the survey data. See Table 6 for a listing of descriptors used.

Health status of the care receiver was not available from the survey, but primary mental disorder and illness duration are somewhat representative of health status, so were chosen as profile details. From the mental illness literature, duration of caregiving and frequent co-residence, were identified as potential sources of cost. Co-residence was not specified in the data, however, care in the caregiver's home was specified. For the purposes of this study, this was chosen to represent co-residence.

Lack of survey information on work history or income for either caregivers or care receivers in the survey data made decisions on whether eligibility criteria would be met uncertain. For the employed care receiver, the earned income average of the region for her gender was used to indicate income. This could not be applied, however, to the retired caregivers, who were not yet seniors. Several income scenarios, therefore, were discussed for these caregivers with potential implications of each included. Since the amount of income of the care receivers was not available from the survey data, discussion of potential income scenarios based on common characteristics of their illness, the eligibility requirements for various forms of assistance and likelihood of employment is included.

Very little precision of profiles was possible given the data available. To develop the profiles, the most frequent answer (mode) was used to determine the descriptors as is appropriate for nominal data. When the mode was only a small percentage, the range was included for ease of understanding the distribution. For ease of description for the answers that contained a range, the year in which the mid point of the range falls was chosen for the profile. For variables that had more than one equally frequent answer, the entire distribution was taken into consideration and the answer most descriptive of the group was chosen. Details of the three 'high cost' caregiver profiles: daughter, mother and husband are included in the results chapter.

2. Choice of Relevant Policy Domains

Types of costs described in the literature guided choices of policy domains that could contain programs that could reduce these caregivers' costs. Out-of-pocket costs from the literature included paying for medication, transportation, homemaking services, counseling and psychological services, providing a home and paying legal fees. Unpaid labour included tasks such as providing companionship, supervision and crisis support, administering or reminding about medications, assessing condition and monitoring symptoms, helping with arrangements for appointments, advocating for services for the care receiver and providing assistance with some activities such as homemaking, personal care and financial management. Employment-related costs included interruptions at work, taking time off to go with the care receiver to appointments, adjusting work to fit care and forgoing employment to give care.

Policy domains, such as housing and transportation, might include occasional programs that could reduce some of the economic costs of these caregivers, however many of the out-of-pocket expenses and unpaid labour activities that have been described are related to health and treatment and involve caregiving time that may interfere with employment. Caregiving that interferes with employment may threaten the employment security and income security of the caregiver and can result in much economic cost with illnesses that can last a lifetime. Mental illness may threaten the employment security and income security of the care receiver and further increase the costs to the caregiver to pay for goods and services for the care receiver. For these reasons, labour, income security and health domains were chosen.

Labour domain programs.

A large percentage of caregivers of persons with mental illness are employed. Impacts to their employment can result in lifetime costs especially if caregivers have repeated disruptions of their employment or must forgo or reduce employment. Policies that regulate employment rights and responsibilities may impact their present and future employment-related costs of caregiving. These policies can influence how much caregivers can work, their employment conditions and whether they receive employment-related benefits. Their employment may affect income and benefits, out-of-pocket costs, overall financial status and the amount and types of unpaid labour that they can do. Labour laws, standards, codes, statutes and acts that govern employment both federal and provincial levels were examined for potential for reducing these caregiver costs.

Income security domain programs.

Income security programs can greatly impact the caregiver's economic costs. Those who decrease or forgo employment to care for a person with mental illness may compromise their own financial well-being. Those who cannot work because of a mental illness may need much financial assistance from those who care for them. Therefore, income-security programs for both the caregiver and the care receiver were examined because decreasing the financial need of the care receiver can indirectly reduce the caregiver's costs. These included social assistance programs, pension and guaranteed income plans, income tax deductions and credits.

Health domain programs.

People who have mental illness have additional health needs to those of persons without mental illness. The medications that treat their illnesses can sometimes temporarily or permanently damage other body systems and functions (including coordination, muscle control, vision, immune response and many more) and some can have fatal results if they are not carefully monitored periodically with laboratory tests and adjusted. Lifestyle choices during mental illness may not always be health promoting and may result in higher costs for health care as well. If the care receivers cannot meet these needs themselves, caregivers may pay for health related costs.

Health programs that provide or reimburse the costs of medical services, allied health services, medications, equipment such as glasses and services such as dental work can reduce the out-of-pocket expenses of caregivers. Programs that provide a break from caring for the caregiver, such as adult day programs and respite programs, may reduce employment-related costs and also unpaid labour costs. Unpaid labour costs may also be reduced by programs that offer particular kinds of services that otherwise are provided by the caregiver such as case management, transportation for medical appointments and therapeutic activities and assistance with homemaking.

3. Choice of Areas of Canada for Comparison

In order to answer whether public programs in Canada reduce economic costs incurred by these caregivers, information about specific programs was needed. Although some programs are federal, many are provincial or regional and much variation in programs can be found throughout the country. Fast and associates (2000) found that sampling policy information for programs that are available in selected geographic areas was essential because of provincial or regional variation. Regional comparison can illustrate some policy differences that impact on caregivers' costs and such a snapshot of how policy is worked out in a few programs can form the basis not only for policy recommendations in these geographic areas but many also raise future questions about policy implications for caregivers of persons with mental illness throughout Canada.

A region in British Columbia and one in New Brunswick were chosen for the analyses to address Research Question 2. These provinces were chosen because they have programs that may be of particular interest for decreasing these caregivers' costs. British Columbia is of special interest concerning caregiver employment costs because they were one of the first provinces to institute family responsibility leave policies. In 2000, New Brunswick also instituted family responsibility leave.

Each province has chosen different strategies to address health/illness needs in the home and community. New Brunswick was one of the first areas to provide home acute health programs that were called "hospital without walls" in 1981 (Ferguson, 2002). British Columbia pursued a more traditional pattern of home care provision. Variation in such health programs operating in the community may differentially affect the out-of-pocket expenditures, employment-related losses and unpaid labour of caregivers of persons with mental illness.

Programs related to the health of the person with mental illness are administered at the health region level. Since there may be program differences among health regions in the same province, one health region was chosen within each province. The two health regions were chosen because they contained a similar population census agglomeration around a small city isolated from any large urban area. Small cities were chosen because some large urban areas operate unique and often experimental programs with special funding. The two small cities that were chosen differ in population size within the geographic city limits, however, the number of persons living in the census agglomeration area is similar. Census agglomeration is determined based on commuting flows (Statistics Canada, 2002, December 17). Both those who live in the small city and those who are in commuting distance would be likely to access programs offered within these cities. The census agglomeration areas chosen surround and include Cranbrook, British Columbia and Bathurst, New Brunswick. Demographic information for the areas was obtained from the most recent available census from the 2001 Community Profiles (Statistics Canada, 2004a).

Map 1: Cranbrook, British Columbia

Cranbrook, British Columbia (city population 18,476 and census agglomeration of 24,275) is located in western Canada in the East Kootenay range of the Rocky Mountains. It lies in the southeastern edge of British Columbia. It is in the East Kootenay Health Region, which is one of four regions in the Interior Health Authority. The Cranbrook C. A. has an average population density of 5.3 persons per square kilometer and covers 4,552.54 kilometers.

YUKON TERRITORY
TERRITOIRE DU YUKON
CANADA
BRITISH COLUMBIA
COLOMBIE-BRITANNIQUE
LEGEND / LÉGENDE
Provincial capital / Capitale provinciale
Other populated places / Autres lieux habités
International boundary / Frontière internationale
Provincial boundary / Limite provinciale
ALBERTA
PACIFIC OCEAN
OCÉAN PACIFIQUE
Scale / Échelle
UNITED STATES OF AMERICA
ÉTATS-UNIS D'AMÉRIQUE
http://atlas.gc.ca

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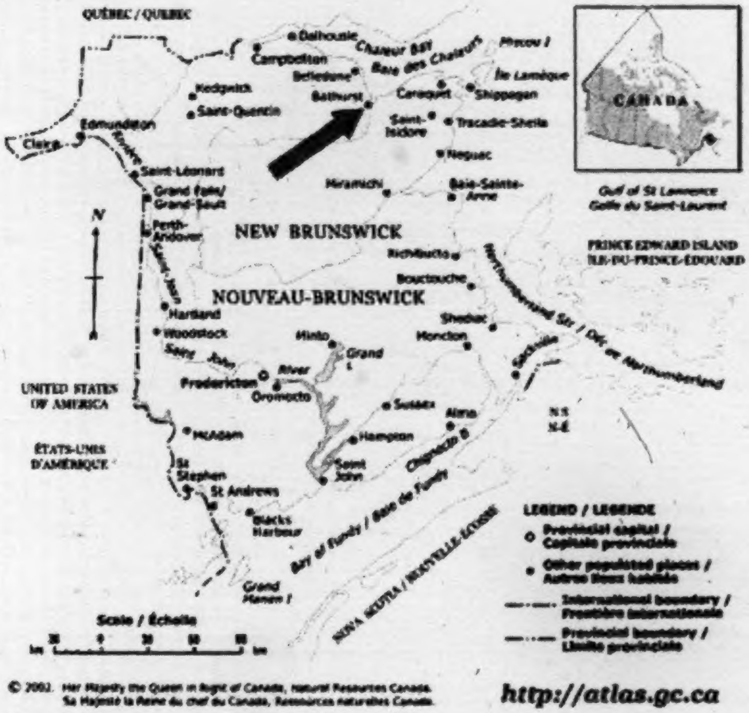
The unemployment rates for the Cranbrook C. A. were 11.4% for men and 9.1% for women, which is higher than the national averages of 7.6% for men and 7.2% for women. The average total earnings of persons in the Cranbrook C. A. who reported earnings in 2000 were $36,377 for men and $20,706 for women. The population for Cranbrook C.A. is increasing as is the population of the province.

Map 2: Bathurst New Brunswick

Bathurst, New Brunswick (city population 12,924 and census agglomeration of 23,935) is located in eastern Canada on the Baie des Chaleur in the northeastern portion of New Brunswick in Health Region 6. The Bathurst C. A. has an average population density of 14.7 persons per square kilometer and covers 1,627.56 kilometers.


QUÉBEC / QUÉBEC
Dalhousie
Chaleur Bay
Baie des Chaleurs
Miscou I
Campbellton
Belledune
Île Lamèque
Kedgwick
Bathurst
Caraquet
Shippagan
Saint-Quentin
Saint-Isidore
Tracadie-Sheila
Edmundston
Clair
Neguac
Saint-Léonard
Miramichi
Baie-Sainte-Anne
Grand Falls/Grand-Sault
Perth-Andover
N
NEW BRUNSWICK
Richibucto
NOUVEAU-BRUNSWICK
Bouctouche
Hartland
Shediac
Woodstock
Minto
Moncton
Grand L
Saint John River
Fredericton
Oromocto
Sackville
UNITED STATES OF AMERICA
ÉTATS-UNIS D'AMÉRIQUE
Sussex
Alma
McAdam
Hampton
St Stephen
Saint John
St Andrews
Blacks Harbour
Bay of Fundy / Baie de Fundy
Grand Manan I
NOVA SCOTIA / NOUVELLE-ÉCOSSE
N.S. N.-É.
CANADA
Gulf of St Lawrence
Golfe du Saint-Laurent
PRINCE EDWARD ISLAND
ÎLE-DU-PRINCE-ÉDOUARD
LEGEND / LÉGENDE
Provincial capital / Capitale provinciale
Other populated places / Autres lieux habités
International boundary / Frontière internationale
Provincial boundary / Limite provinciale
Scale / Échelle
km 20 0 20 40 60 km
© 2002. Her Majesty the Queen in Right of Canada, Natural Resources Canada.
Sa Majesté la Reine du chef du Canada, Ressources naturelles Canada.
http://atlas.gc.ca

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The unemployment rates for the region were 14.5% for men and 10.7% for women compared to the national average of 7.6% for men and 7.2% for women. The average total earnings of persons in the Bathurst C. A. who reported earnings in 2000 were $33,886 for men and $18,887 for women. The population of the Bathurst C. A. is decreasing as is the population of the province.

4. Document Gathering and Scanning Process

Documents including statutes, regulations, laws and program information related to programs that could reduce caregiver costs both directly and indirectly were gathered from publicly-accessible government websites from each of these three chosen domains, from each relevant level of government, for each of the two regions over a period of three months. Clarification was requested by email or telephone from numbers listed on the websites for program information that was unclear. Each document was scanned for eligibility criteria, benefits, user fees and other associated costs of use and the programs were briefly described. Appendix C contains a list of the documents that were collected and reviewed.

5. Analysis of Program Impacts on Caregiver Costs

Program eligibility criteria were compared with the descriptors for each caregiver profile (see Table 13 for complete table of program eligibility requirements obtained through the program impact analysis) in order to determine likeliness of eligibility for programs. Types of benefits, user fees and associated costs for those who would be eligible were described. Differences in caregiver cost reduction for the two regions were contrasted. Cost impacts were summarized in tabular form at the end of each section. Labour and health domains each form one section and there are three sections for the income security domain.

CHAPTER 4: RESULTS

Research Question 1

1. *Does incurring of high costs vary by gender and relationship for primary caregivers of community-dwelling adults with mental illness in Canada?*

Table 1 shows that high costs are distributed among persons in many relationships and both genders. Although most caregivers who incurred high costs were close relatives, some who were distantly related or not related at all incurred high costs through caregiving. The small size of the sample yielded many relationship groups that were so small that we cannot draw definite conclusions and these are shown in the shaded areas in Table 1. For instance, in some cases, all of the caregivers from a distant relationship that were surveyed incurred high costs as is illustrated by the nieces. Whether this would be the case with larger numbers of nieces is unknown, but this does show that high costs are not limited to close family. The small groups, however, are retained in the table to demonstrate the variety of relationships caring and those incurring high costs

The types of high costs the caregivers incurred varied widely across the relationships categories. However, few of the relationship categories were found to be statistically more likely to experience high costs. Daughters were found more frequently to have high unpaid labour costs than other caregivers (Pearson's chi square 10.989, two-tailed p=.001). Nieces also showed a strong association with high cost for unpaid labour (Fisher's Exact Test two-tailed p=.023), but, as mentioned, the number of nieces (3) was far too small to conclude anything with any certainty. Limited association, however, is not surprising, considering that respondents in so many of the relationships categories incurred high costs. This indicates that if one is a caregiver they are likely to have at least one kind of high cost regardless of their relationship with the care receiver (when gender is included with relationship).

Although there are more caregiver relationships represented in some kinds of high costs for females and two male caregiver relationships (brothers-in-law and nephews) did not experience any high costs, it is not clear from Table 1 whether gender itself makes a difference for incurring high costs, so step 2 follows.

Table 1: Number of Persons Incurring High Costs
Note: table is ordered according to proportion of the caregiver population

N=298	Percentage of 298 caregivers	Quit or Retired Early for Caregiving n=17/294	'Significant' Job Disruption N=150/293	>$400 per Month in Out-of-pocket Cost n=33/272	'Significant' Financial Difficulty n=62/293	High Unpaid Labour n=86/298
Mother n=53	17.8%	4	34	8	16	13
Female Spouse/ Partner n=42	14.1%	4	20	5	12	12
Male Spouse/ Partner n=39,	13.1%	4	21	6	9	14
Daughter n=39	13.1%	2	15	1	4	20**
Unrelated Female n=31	10.4%	1	13	2	5	9
Sister n=25	8.4%	--	10	4	5	4
Father n=16	5.4%	1	8	2	6	3
Brother n=11	3.7%	--	4	--	--	1
Unrelated Male n=9	3%	--	5	1	2	--
Son n=8	2.7%	--	7	1	1	2
Grand-daughter n=4	1.3%	--	2	1	--	2
Grandmother n=3	1%	--	3	1	1	--
Niece n=3	1%	1	3	--	--	3*
Daughter-in-law n=3	1%	--	--	--	--	1
Mother-in-law n=2	0.7%	--	--	1	--	--
Aunt n=2	0.7%	--	2	--	--	--
Brother-in-law n=2	0.7%	--	--	--	--	--
Nephew n=2	0.7%	--	--	--	--	--
Stepmother n=1	0.3%	--	1	--	--	--
Son-in-law n=1	0.3%	--	1	--	1	1
Great-Grandson n=1	0.3%	--	--	--	--	1
Sister-in-law n=1	0.3%	--	1	--	--	--

*p=<.05 (but number too small to draw definite conclusions) **p=<.001

Table 2 shows that women are represented over twice as often as men within the caregiver sample. However, the null hypothesis is supported: there were no significant differences in distribution of costs for men and women (using Pearson's Chi Square analysis). This indicates that gender alone does not predict high costs, but that both men and women are likely to experience high costs if they are caregivers and that women are far more likely to become caregivers (see further discussion in Chapter 5).

Table 2 Distribution of High Cost by Gender of the Caregiver

	Number & (%) of 298 caregivers	Number & % of Those Who Quit or Retired Early for Caregiving n=17/294	Number & % of Those With 'Significant' Job Disruption n=150/293	Number & % of Those With >$400 per Month in Out-of-pocket Cost n=33/272	Number & % of Those With 'Significant' Financial Difficulty n=62/293	Number & % of Those With High Unpaid Labour n=86/298
Females	209 (70.1%)	12 (70.6%)	104 (69.3%)	23 (69.7%)	43 (69.4%)	64 (74.4%)
Males	89 (29.9%)	5 (29.4%)	46 (30.7%)	10 (30.3%)	19 (30.6%)	22 (25.6%)

Table 3 shows the proportion of those with high costs across relationship categories. This shows that a high proportion of the costs of caregiving are being borne by those who most frequently become caregivers (i.e. close family members) as would be expected considering their prevalence in the caregiver sample. However, the data show that persons in some relationships are incurring high cost more frequently than would be expected given their proportion of the caregivers if there is no difference according to relationship. Although these are not statistically significant differences, concentration of costs among certain relationships is evident. We can also note that this greater representation among those who have high costs is occurring in multiple areas for some relationships. Mothers are over-represented in four areas of high costs. Both male and female spouses are more highly represented among those with high cost, but for male spouses this occurs in all five areas of cost including being almost twice as likely to quit or retire early than we would expect given their proportion of the population.

Table 3: Proportion of High Cost Borne by Each Relationship
Note: table is ordered according to proportion of the caregiver population

N=298	% of 298 Caregivers	% of Those Who Quit or Retired Early for Caregiving n=17/294	% of Those With 'Significant' Job Disruption n=150/293	% of Those With >$400 per Month in Out-of-pocket Cost n=33/272	% of Those With 'Significant' Financial Difficulty n=62/293	% of Those With High Unpaid Labour n=86/298
Mother n=53	17.8%	**23.5%**	**22.7%**	**24.2%**	**25.8%**	15.1%
Female Spouse/ Partner n=42	14.1%	**23.5%**	13.3%	**15.2%**	**19.4%**	14%
Male Spouse/ Partner n=39,	13.1%	**23.5%**	**14.0%**	**18.2%**	**14.5%**	**16.3%**
Daughter n=39	13.1%	11.8%	10.0%	3.0%	6.5%	**23.3%**
Unrelated Female n=31	10.4%	5.9%	8.7%	6.1%	8.1%	10.5%
Sister n=25	8.4%	--	6.7%	12.1%	8.1%	4.7%
Father n=16	5.4%	5.9%	5.3%	6.1%	9.7%	3.5%
Brother n=11	3.7%	--	2.7%	--	--	1.2%
Unrelated Male n=9	3.0%	--	3.3%	3.0%	3.2%	--
Son n=8	2.7%	--	4.7%	3.0%	1.6%	2.3%
Granddaughter n=4	1.3%	--	1.3%	3.0%	--	2.3%
Grandmother n=3	1.0%	--	2.0%	3.0%	1.6%	--
Niece n=3	1.0%	5.9%	2.0%	--	--	3.5%
Daughter-in-law n=3	1.0%	--	--	--	--	1.2%
Mother-in-law n=2	0.7%	--	--	3.0%	--	--
Aunt n=2	0.7%	--	1.3%	--	--	
Brother-in-law n=2	0.7%	--	--	--	--	--
Nephew n=2	0.7%	--	--	--	--	--
Stepmother n=1	0.3%	--	0.7%	--	--	--
Son-in-law n=1	0.3%	--	0.7%	--	1.6%	1.2%
Great-grandson n=1	0.3%	--	--	--	--	1.2%
Sister-in-law n=1	0.3%	--	0.7%	--	--	--
Totals†	100%	100%	100.1%	99.9%	100.1%	100.3%

† percentages do not total 100 due to rounding

So the question becomes how to identify who, among these many varied relationships, would be especially at risk of having high costs. One way is to look at the within group likelihood. When we look at the within group variation for those who most frequently are the caregivers, we see a greater likelihood for persons in some relationships to incur high costs. Table 4 shows that for some groups the majority of persons in that relationship group have a high cost. 'Significant' job disruption was a very common cost for mothers, with 64.2% of mother caregivers of adults with mental illness experiencing this cost. It was also common for male spouses with 53.8% of them experiencing 'significant' job disruption (see Table 4). Over half (51.3%) of all the daughters who were giving care experienced high unpaid labour costs.

Table 4: Proportion of Each Relationship Group (n ≥ 30 cases) Incurring High Cost
Note: table is ordered according to proportion of the caregiver sample

N=298	% of the total caregiver sample	Quit or Retired Early for Caregiving n=17/294	'Significant' Job Disruption n=150/293	>$400 per Month in Out-of-pocket Cost n=33/272	'Significant' Financial Difficulty n=62/293	High Unpaid Labour n=86/298
Mother n=53	17.8%	7.5%	**64.2%**	15.1%	30.2%	24.5%
Female Spouse/ Partner n=42	14.1%	9.5%	47.6%	11.9%	28.6%	28.6%
Male Spouse/ Partner n=39,	13.1%	10.3%	**53.8%**	15.4%	23.1%	35.9%
Daughter n=39	13.1%	5.1%	38.5%	2.6%	10.3%	**51.3%**
Unrelated Female n=31	10.4%	3.2%	41.9%	6.5%	16.3%	29%

High costs do not necessarily occur in isolation. Having more than one high economic cost concurrently could increase financial difficulty for caregivers. Analyses of other high costs for just the mothers and husbands who had 'significant' job disruption and for just the daughters who had high unpaid labour costs showed that they had a high risk for other concurrent high costs. Table 5 shows that over half (52.6%) of the daughters also experienced 'significant' employment disruption and 57.5% of the husbands also incurred high unpaid labour costs. One third of the male spouses also experienced significant financial difficulty and almost one third (31.3%) of the mothers also experienced financial difficulty.

Table 5: Concurrent High Costs by Percentage of the Relationship Category

	Daughters with High Unpaid Labour Costs n=20 (6.7% of the total caregiver sample)	Mothers with 'Significant' Job Disruption n=34 (11.4% of the total caregiver sample)	Male spouses with 'Significant' Job Disruption n=21 (7.% of the total caregiver sample)
Quit or Retired Early to Give Care	10.5%	11.8%	19%
'Significant' Job Disruption	**52.6%**	--	--
>$400 per Month in Out-of-Pocket cost	9.1%	10%	9.5%
'Significant' Financial Difficulty	10%	**31.3%**	**33.3%**
High Unpaid Labour	--	23.5%	**57.5%**

Research Question 2

2. *Do current public programs in Canada reduce economic costs incurred by caregivers who experience high costs?*

The first step toward answering this question involved creation of caregiver profiles to use as example of caregivers for evaluating impacts of programs.

Creation of 'High Cost' Caregiver Profiles

Based on the results of Research Question 1, the three 'high cost' caregiver examples were daughters, mothers and husbands.[2] All were more likely than not to experience at least one high cost and they had high risk of experiencing more than one cost concurrently.

Table 6 shows the most frequent answers to survey questions that supply data describing these 'high cost' caregivers, their care receiver, or dyadic descriptors. To link caregivers with care receivers in the profiles for ease of memory, both were given a name starting with the first letter of the caregiver's relationship: names in the daughter profile start with 'D,' the mother profile with 'M," and the husband profile with 'H."

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[2] From this point on, the term 'husband' will be used because the mode is heterosexual, while acknowledging that there are a minority of same sex care dyads in the survey.

Table 6: Most Frequent Descriptors for 'High Cost' Caregiver Profiles

	Daughters with High Unpaid Labour (n=20 of the 39 daughter caregivers)	Mothers Who Described 'Significant' Job Disruption (n=34 of the 53 mother caregivers)	Husbands Who Described 'Significant' Job Disruption (n=21 of the 39 husband caregivers)
Spouse in the Home?	*Yes (65.0%)	*No (57.6%)	--
Children under 16 present?	*No (84.2%)	*No (93.8%)	*No (85.0%)
Caring for other ill or disabled persons?	*No 95.0%	*No (76.5%)	*No (90.5%)
Labour Force Status	*Employed full time (30.0%) Note: an additional 30.0% were employed part-time or self-employed.	*Retired (47.1%) Note: an additional 29.4% described themselves as a homemaker.	*Retired (52.4%) Note: the next most frequent choice was 14.3% currently seeking work.
Age of Caregiver	*Equal 35-44 or 45-54 yrs. (30.0% each) Midpoint between the 2 modes chosen. Range 18 to >65yrs.	*55-64 yrs. (26.5%) Range 35 to >65yrs	*55-64 yrs. (33.3%) Range 18 to >65yrs.
Gender of Care Receiver	*Female (90.0%)	*Male (67.6%)	*Female (90.5%)
Age of Care Receiver	*75-84 yrs. (40.0%) Range 45 to 85yrs.	*35-44 yrs. (35.3%) Range 18-64 yrs.	*45-54 yrs. (28.6%) Range 18-84 yrs.
Primary Mental Disorder	*Mood Disorder (65.0%)	*Schizophrenia (61.8%)	*Mood Disorder (71.4%)
Illness Duration	*Long-term (90.0%)	*Long-term (97.1%)	*Long-term (90.5%)
Duration of Care	*6-10 yrs. (30.0%) Range <1mo. to >10yrs.	* >10 yrs. (47.1) Range 1 to >10yrs.	* >10 yrs. (33.3%) Range 1mo. to >10yrs
Location of Care	*Caregiver's Home (70.0%)	*Caregiver's Home (61.8%)	*Caregiver's Home (100%)

* indicates most frequent answer followed by percentage

Daughter Caregiver Profile

Darla, age 44, gives care in her own home to her mother Donna who is 79 years old. Mom's mood disorder is long-term and Darla has been caring for 8 years now. She is married and living with her husband. Darla stays very busy with her care of her mother and finds that there is not much free time and that her employment is being disrupted a lot.

Mother Caregiver Profile

Mary, age 59, has been caring in her own home for her son Mark who is 39 years old. She is a lone mother. Mark's schizophrenia has required a lot of help from her for well over 10 years now. She is retired.

Husband Caregiver Profile

Hal, age 59, has been caring for his wife Helen, age 49, in their home for well over 10 years now. Helen's long-term mood disorder has required a lot of help from him. He has very little time for working to supplement his retirement income and giving care disrupts doing that a lot.

Results of Document Scan & Program Impact Analyses

Labour Domain Scan

Labour programs were examined because so many caregivers of persons with mental illness are employed and the literature shows that work may be disrupted, sometimes without warning, as crises related to the illness arise. For this reason leave policies were examined.

Legislative powers concerning labour are divided between the federal and provincial governments based on Sections 91 an 92 of the Constitution Act 1867 (Human Resources and Social Development Canada, 2003, March 10). Federal government jurisdiction extends to only approximately 10% of labourers within Canada, such as those employed by services that are of national, international or interprovincial importance, such as those concerning railways, highways, waterways, banks, radio and television broadcasting, some agriculture and natural resources connected activities and many Crown corporations (Human Resources and Social Development Canada, 2005, November 18).

The only current federally legislated leaves protecting employment because of family care responsibilities include maternity leave, parental leave, compassionate care leave and bereavement leave (Department of Justice Canada, 2006, March 3c), none of which would be applicable to caring for an adult with mental illness.

1. Family responsibility leave.

Family responsibility leave for British Columbia.

The Employment Standards Act of British Columbia entitles employees to a maximum of 5 days per employment year in unpaid leave to "meet responsibilities related to the care, health or education of any member of the employee's immediate family" which is further defined as "spouse, child, parent, guardian, sibling, grandchild or grandparent of an employee, and any person who lives with the employee as a member of the employee's family." (British Columbia Ministry of Labour and Citizen's Services, 2006, August, p. 2). However, "Any time taken off on any day (*even one hour*) qualifies as one day for purposes of this section, unless the employer and employee agree otherwise." (Queen's Printer for Government of British Columbia, 2006, March 31, *see definition of "day" in s.1 of the Act;* British Columbia Ministry of Labour and Citizen's Services, n.d.).

Family responsibility leave for New Brunswick.

The New Brunswick Employment Standards Act states that "An employer shall, upon the request of an employee, grant the employee leaves of absence without pay of up to three days during a twelve calendar month period to meet responsibilities related to the health, care or education of a person in a close family relationship with the employee." (Government of New Brunswick , 2006, March 10a, S*ection* 44.022(1)) They define "close family relationship" as "the relationship between persons who are married to one another, between parents and their children, between siblings and between grandparents and their grandchildren, and includes a relationship between persons who, though not married to one another and whether or not a blood relationship exists, demonstrate an intention to extend to one another the mutual affection and support normally associated with those relationships first mentioned" (Government of New Brunswick , 2006, March 10a , part I, Definitions). The legislation protects persons from loss of their position and pay level due to these days being taken. There is no statement in the Act of any limitation of whether the three days' time may be divided into partial days.

2. *Employment Insurance benefits.*

Employment Insurance (EI) is intended to provide short term income security for workers who are presently unemployed for a reason beyond their control. Caregiving other than parental leave does not make one eligible for any Employment Insurance benefits, except compassionate care leave benefits, which apply only to those giving care to individuals in certain relationships who are likely to die within 26 weeks as attested by a physician (see Human Resources and Social Development Canada, 2006, August 16).

Employment Insurance does, however, offer a sickness benefit to workers who become unable to work due to illness, injury, or being quarantined. If a care receiver worked during the previous 26 weeks, they may be eligible for 15 weeks of EI sickness benefit, which could benefit the caregiver indirectly. The payment rate is equivalent to 55% of their averaged weekly income during that 26 week period divided by a factor reflective of the unemployment rate for the area or the number of weeks worked (whichever is greater). The maximum rate is $413 per week. Repeated illness episodes may render the individual ineligible for sickness benefits due to previously existing conditions that might preclude employment (Human Resources and Social Development Canada, 2006b) and the medical certificate attesting to illness requires a statement about the expected duration of the illness (Human Resources and Social Development Canada, 2006, September 25). The care receivers would be required to submit proof that they were available for work if they had not been ill, including information on "reason for separation, the claimant's personal situation, his or her intentions, requirements and restrictions in relation to the labour market" (Human Resources and Social Development Canada, 2006, May 23, S*ection 11.3.0, para., 3).* The only user fee described is that the claimant is required to pay any physician fees for the certificate. Other sickness benefits from employers or other insurance have to be used first before EI sickness benefit is available. However, if a person receives social assistance while awaiting EI, the amount of the social assistance received is deducted and repaid from EI payments (Service Canada. (n.d.b).

Analysis of Impacts of Labour Programs on Caregiver Costs

Labour programs offer little potential reduction in caregiver costs. None of the existing federal leave programs could serve to reduce costs of the profiled caregivers. Provincial family responsibility leave prevents some loss of future income and benefits by assuring that the caregiver's employment is not lost because of temporary need to attend to care responsibilities. The daughter caregiver is a close enough relative to qualify for this program in either province. This much time may not help her much, however. Three days or even five days could be quickly expended in the many activities that she does daily and those that depend on the schedules of others. These activities cannot necessarily be adjusted around her own work schedule (e.g,, arranging and coordinating services and appointments and going to appointments with her mother). Crisis times may require more than the three days in New Brunswick or the 5 days in British Columbia would allow for just trying to arrange for someone to stay with her mother. Lack of consistency of interpreting whether 1 hour = 1 day in British Columbia could make a big difference when a few hours need to be spent periodically accompanying her mother to treatment appointments. Conflicts with employment due to high unpaid labour activity may also result in higher out-of-pocket costs as others are hired to take on some of the caregiver's responsibilities. Conflicts with employment due to inflexible requirements for care activities may also influence the kind of employment the caregiver accepts. For example, this might involve choosing to work a less desirable job that is more flexible or less desirable hours such as night shift, in order to be available for appointments that often occur in the day time.

Employment Insurance benefits do not apply directly to any of the 'high cost' caregiver profiles (unless they are caring for someone who is terminally ill), which is not likely to be the case for any of these care receivers). Employment Insurance also would be unlikely to benefit Darla's mother, who is beyond the likely age of employment even if she was well. Indirect reduction of costs because of benefits that Mary's son or Hal's wife might receive would depend on their work history and their illness history, but policy concerning repeated illnesses may well rule out any benefit to them. Employment insurance is not designed for episodic or long-term health problems.

Table 7: Comparison of Impacts on Caregiver Costs of Labour Programs by Region
Key: CG=Caregiver, CR=Care Receiver

	Daughter Caregiver, Darla		Mother Caregiver, Mary		Husband Caregiver, Hal	
	Cranbrook Area	Bathurst Area	Cranbrook Area	Bathurst Area	Cranbrook Area	Bathurst Area
Family Responsibility Leave	↓ CG employment-related costs (5 days or 5 hrs.?)	↓ CG employment-related costs (3 days)	No reduction-retired	No reduction - retired	No reduction-retired	No reduction - retired
Employment Insurance	No reduction likely	No reduction likely	Little, if any, reduction (if CR was working enough to qualify)	Little, if any, reduction (if CR was working enough to qualify)	Little, if any, reduction (if CR was working enough to qualify)	Little, if any, reduction (if CR was working enough to qualify)

In conclusion, labour programs offer little potential for reducing the costs of caregivers who are dealing with long-term and unpredictable illnesses.

Income Security Domain Scan

Programs that could provide income for caregivers as well as those that could indirectly reduce the costs of caregivers by providing or enhancing income of persons with mental illness so that they could perhaps purchase their own goods and services were examined. These programs include 1) social assistance and disability programs; 2) pension plans and guaranteed income programs, and 3) income tax deductions, credits and rebates.

1. Social assistance programs and disability programs.

Assurance of a minimal level of economic support is the responsibility of Provinces and Territories. Both British Columbia and New Brunswick recently have revised their social assistance systems by combining employment and assistance. Both express the intent to assist individuals to work for themselves and become as independent as possible as quickly as possible. This is reflected in time limitations of assistance and requirements to be preparing for or pursuing employment when not employed in order to receive social assistance. However, both provinces make allowances for persistent barriers to employment and long-term needs.

Social assistance programs in British Columbia.

British Columbia Ministry of Employment and Assistance (British Columbia Ministry of Employment and Income Assistance, n.d.d) combines provincial employment and income security programs for both able-bodied persons and persons with disabilities with the intention to "assist people temporarily while they find work, and to assist those who are unable to fully participate in the workforce" (British Columbia Ministry of Employment and Income Assistance, n.d.f, p. 2).

In 2002, provincial legislation replaced several employment and income assistance acts with two acts, the *Employment and Assistance Act 2002* (Government of British Columbia, 2005b) and the *Employment and Assistance for Persons with Disabilities Act 2002* (Government of British Columbia. (2006, July 1). Both govern employment and/or income assistance, hardship assistance and supplements but they are for recipients with different life situations. Under these Acts, persons are considered either employable, temporarily having no employment obligation (NEO), a person with a disability (PWD), or a person with persistent multiple barriers to employment (PPMB). Minimal income, a housing allowance, savings on a bus pass, payment of

Medical Services Plan premiums, no-deductible Pharmacare, optical care and emergency dental coverage are benefits. Because these programs are payers of last resort, potential applicants are required to submit a three-week work search record documenting that they have sought work and have sought other forms of assistance including liquidating some assets (they may retain a life insurance policy with a maximum $1500 surrender value, a $5000 value vehicle and $150 cash per person) (British Columbia Ministry of Employment and Income Assistance. (n.d.b). A full disclosure of all income and assets is required in order to apply.

Eligibility for income assistance is based on income, assets, age and number of family members, as well as strict adherence to a specified "employment plan" for each family unit member 16-65 years of age that involves working, preparing for work and/or seeking work. Family is defined as the person receiving the benefit and all of their dependents. Dependents include anyone living with the recipient and sharing income or assets or things obtained with these (Government of British Columbia, 2005b, Section 1(1)). Benefits are limited to 24 months out of each 5 years for persons not classified as PWD or PPMB British Columbia Ministry of Employment and Income Assistance. (2005, November 21). Working family members' income is subtracted dollar for dollar from the assistance with certain income exemptions. Pension income is also deducted from social assistance. Exemptions are slightly higher for PWD and PPMB designations than for others (see British Columbia Ministry of Employment and Income Assistance, 2006, February 2).

There are 25 exemption categories that allow for temporary exclusion from employment obligation. These include such characteristics as age over 65 years, mental or physical condition precluding "employment plan" activities, being a sole parent (foster parent or other relative) caring for a child that is under 3 years of age or severely disabled, institutional placement, flight from an abusive relationship, and those living with and caring for a spouse with a physical or mental condition (British Columbia Ministry of Employment and Income Assistance, 2005 November 21). Time limits for the 'temporary' exemption from employment to give care are not stated in the documents.

For the purposes of British Columbia social assistance, disability is defined as a condition likely to persist for over 2 years duration or to recur periodically for extended time periods and to restrict ability to perform activities of daily living to the extent that assistive measures such as equipment, assistance animals and/or significant help or supervision by others are necessary as attested by a medical professionals (Government of British Columbia, 2005b). Both physical and mental abilities are assessed in the 24-page application for a persons with disability (PWD) designation, but employability is not a criterion for determining disability in this case (British Columbia Ministry of Employment and Income Assistance, 2003, January 29). If care recipients do qualify as PWD they receive a maximum of $531.42 per month plus a $75 to $325 shelter allowance (British Columbia Ministry of Employment and Income Assistance, 2005, January 1a). The shelter allowance is 'minimal' for those living with family in a room and board situation unless they are charged for rent.

Individuals who continue to require financial assistance despite reasonable attempts to support themselves by employment may be eligible for assistance as persons with persistent multiple barriers (PPMB). Criteria include consistent and long-term need for assistance, severe barriers to employment resulting in a score of 15 or more on an employability screen (see Government of British Columbia, 2005, August 1, Schedule E), and medical conditions lasting one or more years with likely continuation or recurrence that interferes with employment activities. The income supplementation for this category is very small with an earnings exemption similar to that of persons with disabilities, no time limitation and social assistance supplementary health benefits, as well as some extended therapies, including additional dental services and some medical transportation (British Columbia Ministry of Employment and Income Assistance, 2006, March 23)

British Columbia Employment programs for persons with disabilities (EPPD).

For persons who have been designated as PWD or PPMB, the Ministry of Employment and Income Assistance offers benefits to help them obtain and maintain employment (British Columbia Ministry of Employment and Income Assistance, 2004, May 18). Job-related training benefits include developing skills with computers, making decisions and preparing résumés. Coaching support is available for analyzing jobs and tasks, job placement and employment crises management. Planning, information on how to begin a business and supportive management of crisis situations is available for those who could potentially operate their own business. Several kinds of adaptive supports to increase employment are available, but most of these services would be useful only to persons with physical disabilities (e.g., deaf interpreting, software to assist those with vision disabilities and workplace modifications). No fees were listed for these items and services and no time limits were stated for the crisis support.

Social assistance programs in New Brunswick.

The Government of New Brunswick Ministry of Family and Community Services administers social assistance programs as a payer of last resort generally offering temporary assistance within strict guidelines. The Income Security Act and associated Regulations require that an "approved case plan" be established for each recipient "that supports a conclusion that the recipient may, through employment, be able to cease receiving assistance within a reasonable period of time" (New Brunswick., 2005, September 1, Section 4(0.1).

Recipients are required to prove that they "continue to explore, to the best of their ability, every possibility of financial support, employment, training and education and every possible opportunity for self-sufficiency available to them," (New Brunswick, 2005, September 1, Section 6 (b)) as a condition of receiving support. Other than a few exemptions (such as children's Registered Educational Savings Plans (RESPs), but not Registered Retirement Savings Plans (RRSPs) or insurance policies), assets other than a vehicle, property where they reside and things required to pursue employment income are required to be liquidated and used first for support of the economic household regardless of penalty or economic cost. No modifying clauses were found applying to caregivers of any sort, other than potential provision of child day care based on social and financial need so that parents receiving assistance can work or attend classes or rehabilitation.

Social assistance benefits include a small combined allotment (maximum of $570/month for a single person living in a family situation) (New Brunswick Family and Community Services, n.d.f). to be used for food, clothing, shelter, routine transportation, personal and household items calculated according to the budget deficit method using as the basic unit the "economic household." The ministry sets maximum rates of assistance based on the number of people who live together and share accommodations and food (regardless of relationship, with some exemptions) and the employability of each, then subtracts whatever the recipient(s) receive through employment, child maintenance or other forms of income with some exemption made for self-employment income in one-person enterprises (New Brunswick Family and Community Services 2006, July 27b). Special Needs Benefits based on specific requirements of the person or family receiving benefits also are available including such items as necessities for educational or employment endeavours and medical supplies.

Exemptions from the economic household rule exist for young or single parents in the parental home, disabled people, seniors living with their children, those designated to have long-term needs, those who rent or board in the home, students sharing accommodation, adult children with low income and some persons in transition in their parents' home (recently deinstitutionalized, released from incarceration, etc.). For these persons, social assistance is not based on *all* of the household income (New Brunswick Family and Community Services, 2004, household income section). However, the Social Assistance Manual 2004 states that the parents' income for those who are disabled (over 18 years of age) and live in the parental home is assessed and a portion of the disabled person's shelter component of their benefits is deducted based on the parent's income (0% for under $30,000 to 25% for over $40,000) (New Brunswick Family and Community Services, 2004, blind deaf or disabled section).

Three benefit programs determine the amount of benefits payable. Interim, Transitional and Extended Benefits Program payments are based on assessment of capacity for financial self-sufficiency, barriers to achieving financial self-sufficiency, duration of need for assistance and disability (New Brunswick Family and Community Services, n.d.f.). Interim Assistance is intended to provide temporary help to persons who are expected to become independent rapidly. Transitional Assistance addresses needs of persons who have some employment barriers and some intermittent needs, but who with assistance for a relatively short time period, are expected to achieve financial independence. The Extended Benefits Program provides long-term benefits to persons who are considered disabled or to have long-term needs. Monthly income that a single person can earn without losing any benefits is set at $300 for Interim, $150 for Transitional and $250 for Extended Benefits Plans (New Brunswick, 2005, September 1, *Section 8(2)(e-e.02))*.

For those with long-term problems in New Brunswick, two categories exist: disabled and long-term needs. Disability is determined by a government appointed Medical Advisory Board using the definition of "suffering from a major physiological, anatomical or psychological impairment, as verified by the Medical Advisory Board under Subsection 4(5), that is likely to continue indefinitely without substantial improvement and that causes the person to be severely limited in activities pertaining to normal living" (New Brunswick, 2005, September 1, p. 2). For the long-term needs category, eligibility is based on "one or more significant physiological, anatomical or psychological impairments that render a person unable to engage in social or economic activities for a prolonged period of time and that lead to long-term unemployment, but that are not so major as to render the person disabled" (New Brunswick, 2005, September 1, p. 2).

New Brunswick employment programs for persons with disabilities.

For persons in New Brunswick who pursue vocational rehabilitation because of disability and receive Employment Assistance Services Training and Development Assistance, another definition of disability applies: "disabled person means a person who because of a physical or mental impairment is incapable of pursuing regularly any substantially gainful occupation," (Government of New Brunswick, 2000, June 30, Section 1, definitions). However, no definition for "substantially gainful" is included. Sheltered workshop programs are available for persons eligible for this assistance. This program only takes applicants under 65 years of age, however (Government of New Brunswick, 1991, March 31).

The Training and Employment Support Services (TESS) program of Family and Community Services assists persons with disabilities to obtain employment. Legal residents who are at least 18 years old (or a high school graduate), have plans for employment and have a permanent disability are eligible to receive assistance with preparation for employment and connecting with employers, support for orientation at a job, some ergonomic modifications at the workplace and assistance with development of self-employment plans (New Brunswick Family and Community Services, 2004). Aside from these benefits, Family and Community Services also offers the Career Development Opportunities Program which may assist with costs of such items as training materials, books, clothing and some transportation in order to obtain employment training for clients who have a work plan involving training.

Table 8 Comparison of Impacts of Income Security Social Assistance and Disability Programs by Region on Caregiver Costs
Key: CG=Caregiver, CR=Care Receiver, OOP costs=out-of-pocket costs

	Daughter Caregiver, Darla		Mother Caregiver, Mary		Husband Caregiver, Hal	
	Cranbrook Area	Bathurst Area	Cranbrook Area	Bathurst Area	Cranbrook Area	Bathurst Area
Provincial Social & Disability Assistance Programs	• No CG benefit. CG is not eligible (working). Not worth liquidating assets. • Little or no CR benefit. Although the CR may be eligible for social assistance with no employment obligation because of her age, the whole family's income would be considered for calculation and pensions would be counted as income.	• Little or no CG benefit. CG is not eligible (working). Not worth liquidating assets. • Little or no CR benefit. Although CR may be eligible for social assistance (because elderly) and would be considered a separate economic household, pension income would be deducted.	• No CG benefit. CG is working age, no exemption for caregiving. Any income (including pensions) would be subtracted from social assistance. Not worth liquidating assets. • CR would be likely to qualify for PWD or PPMB due to disability definition, if qualifies may ↑ CR income →↓ CG OOP costs, but the whole family's income would be considered for calculation of benefit. • If CR does qualify, minimal shelter allowance with co-residence unless charged rent.	• No CG benefit. CG is working age, no exemption for caregiving. Any income (including pensions) would be subtracted from social assistance. Not worth liquidating assets. • Little CR benefit. Although CR may be eligible for social assistance & would be considered a separate economic household, the rule decreasing housing allowance if living in parent's house applies	• No CG benefit. CG is working age, although CG could be temporarily exempted from employment obligation because caring for spouse with mental illness, any income (including pensions) would be subtracted from social assistance. • Although the CR may be eligible for social assistance with temporary no employment obligation because of a mental condition, not certain if qualifies for PWD or PPMB because of disability definitions. • The whole family's income would be considered for calculation of CR benefit. • If CR does qualify, minimal shelter allowance with co-residence unless charged rent.	• No CG benefit. CG is working age, no exemption for caregiving. Any income (including pensions) would be subtracted from social assistance. Not worth liquidating assets. • Although CR may be eligible for social assistance, spouse's income considered for calculation of benefits.
Employment Programs for Persons with Disability (Provincial)	• CG not eligible (not disabled) • No CR benefit. CR not eligible (too old).	• CG not eligible (not disabled) • No CR benefit. CR not eligible (too old).	• CG not eligible (not disabled) • May qualify if CR is considered PWD or PPMD and is able to work, if so, may ↓ CG OOP costs indirectly due to ↑ CR disposable income (if he stays employed).	• CG not eligible (not disabled) • CR may qualify if ruled permanently disabled, or incapable of gainful employment. if so, may ↓ CG OOP costs indirectly due to ↑ CR disposable income	• CG not eligible (not disabled) • CR could qualify if PWD or PPMB, but may not qualify due to definition of disability.	• CG not eligible (not disabled) • CR may qualify if ruled permanently disabled, or incapable of gainful employment, if so, may ↓ CG OOP costs indirectly due to ↑ CR disposable income)

Analysis of Impacts of Social Assistance and Disability Programs

The results for this section are summarized in Table 8. Although social assistance could replace some caregiver current income and benefits, it is temporary, at best, if they qualify. All three 'high cost' caregivers profiled are of working age and would be expected by social assistance programs to work, seek work, or prepare for work. In either province, going on social assistance requires liquidating most assets (except house, low equity vehicle, work tools and children's education saving plan) regardless of loss and using the amounts gained from these assets first before applying for assistance. It would be difficult to ever recuperate from such depletion or even to pay for repairs if something malfunctions or if substantial out-of-pocket expenditure is needed for caregiving. Although we do not know the caregiver's income, the average earned income for either province exceeds social assistance. Whether either the mother caregiver or the husband caregiver is receiving a pension (or, for the mother, perhaps a divorce settlement) is unknown. Employment income and other income is deducted from social assistance, so those who work or receive pensions would not be likely to benefit from social assistance. There is no caregiving exemption that applies (except temporary exemption for spouse caregivers in British Columbia). There would be little if any direct benefit from social assistance.

Out-of-pocket costs for caregivers might be reduced indirectly, however, through programs that improve the care receiver's economic condition. If the care receiver is able to purchase his/her own goods and services, then these costs, in principle, would not be likely to be paid by the caregiver. The care receiver may also qualify for social assistance or some form of work assistance that may be able to help them to work more when they are able.

It is uncertain whether Darla or Hal would benefit much from disability assistance for their care receiver because a mood disorder might not meet the requirements for being deemed disabled in either province. In British Columbia, it would be hard to predict whether the disorder would be likely to persist over 2 years (although many mood disorder episodes do), but periodic recurrence is common.

Whether the need for assistance or supervision during recurrence would be deemed "significant" would be determined on a case-by-case basis. Similarly, in New Brunswick, the requirement of indefinite continuation of the impairment is very likely to be met, but "without substantial improvement" might not be, because there are many medications and other treatments that are effective for improving function of persons with mood disorders. Although the son care receiver, Mark, would probably be deemed disabled because of his schizophrenia and would receive the highest rate of social assistance in either province as well as subsidization of several health benefits, the classification of "disabled" in New Brunswick could still result in out-of-pocket costs for Mary because the housing allocation (for disabled persons who live with their parents) can be reduced based on the parents' income.

Based on social assistance program requirements, persons with mood disorders would be more likely to be judged as persons with problems rather than with disabilities in either province. In British Columbia they *might* qualify as persons with persistent multiple barriers (PPMB), based on their medical condition lasting more than one year and being likely to continue or recur and interfere with working. However, to qualify as PPMB they must meet the requirement of having demonstrated "reasonable" attempts to support themselves. A definition of what constitutes "reasonable" proofs for this program was not found in the documents. PPMB support is not time limited and provides a small income and medical benefits. In New Brunswick, they would probably qualify for "long-term needs" social assistance. It is even more difficult to predict whether a person with a mood disorder in New Brunswick would qualify for long-term needs support than for British Columbia. Persons with mood disorders might qualify for this program because of having a long-term psychological impairment that interferes with social and economic activities, resulting in long-term unemployment. The clause "not so major as to render the person disabled" (New Brunswick, 2005, September 1, New *Brunswick Regulation 95-61*, p. 2) is not clear, but the program may provide a small income and subsidization of some health expenses for those who do not qualify as disabled in New Brunswick.

If the care receivers did not qualify for social assistance based on their disability or employment "problems," they might qualify for temporary social assistance in either province. In British Columbia, the requirement for pursuing an employment plan which involves working, seeking work, or training for work can be waived for persons with a mental condition that would prevent them from participating in employment plan activity and is waived for anyone over 65 years of age. However, because they would not be disabled, the entire income of those in the household would be considered for eligibility and for rates of support. New Brunswick, however, exempts some persons from the economic household rule, including seniors living with their children and adult children with low income (low income amount was not defined), so Darla and Mary might benefit indirectly from this without the whole family's income being considered for calculations, but Hal would not.

Employment of the care receiver if they become well enough for work could also reduce caregiver costs. British Columbia's employment programs for persons with disabilities (EPPD) might improve the employability of care receivers who have poor employment qualifications because their illness interfered with their education or opportunities for work experience. However, it cannot remove barriers to employability due to episodes of mental disorder. Whether succeeding at the training but failing at maintaining employment might change their status from PWD or PPMB to "employable" for social assistance determination is a question that should be considered before commencing any employability enhancement training offered through this program. Otherwise, their economic condition may be worsened by the program. Both Mary and Hal might qualify indirectly if their care receivers became well enough to work, but Darla's mother is to old to benefit from this program.

New Brunswick offers two employment programs which are available to persons who are judged to be disabled, but neither would be likely to apply to any of our care receivers. Few persons with a mood disorder, if they receive adequate and effective treatment, would be so incapable of gainful employment that they would require a sheltered workshop environment, nor would they necessarily be considered permanently disabled. Even persons with schizophrenia would generally be able to be treated enough to work at a job in the community when they are well enough, so this might not benefit Mary indirectly either.

In conclusion, social assistance would offer very little benefit with potential to result in significant economic damage to caregivers due to the requirement of liquidating assets. It would not be of benefit when caregiving interferes with employment even for the husband caregiver, although he could perhaps qualify with no employment obligation in British Columbia. Disability benefits are small and uncertain in both provinces for persons with mood disorders. Employment assistance in both provinces is more likely to offer benefit to those with physical disabilities or permanent unchanging disabilities than to persons with mental illness.

2. Pension plans and guaranteed income programs.

Pension programs were examined because Darla's mother is 79 years old and because both Mary and Hal described themselves as 'retired' (although they are each only 59 years old).

Federal public pension plans currently exist in Canada for workers who have contributed to either the Canada (or Quebec) Pension Plans and persons who are over 65 years of age (or for one program, 60-64 and married to a senior), as well as some survivors of these pensioners. Senior supplements to income also exist in both provinces. One other federal personal contributory retirement savings plan, the Canadian Government Annuities Plan, pays benefits but no longer accepts new participants (Government of Canada, 2006, March 3; Government of Canada, 2003, September 11).

Canada Pension Plan (CPP).

Since 1966, the Canada Pension Plan has been providing basic benefits to workers when they retire or become disabled and to the spouse and minor children of plan contributors who die. Canada Pension Plan legislation (Department of Justice Canada, 2006, March 3d) regulates the program. It is supported by obligatory contributions from workers. To be eligible for CPP retirement pension, the individual must be between the ages of 60 and 70 and must have made at least one contribution to the plan. Number of years worked and amount paid into the plan (with some adjustments factored in) affect the monthly rate. Clauses exist to allow excluding 15% of the lowest earning years from the calculation to determine benefit level, excluding months in which there was no or less than usual employment and for excluding some time spent in child rearing (Human Resources and Social Development Canada, 2006, January 5; Human Resources and Social Development Canada, 2006, January 10). The current average monthly payment is $463.95 and current maximum is $844.58 per month. It is indexed annually based on the Consumer Price Index (Human Resources and Social Development Canada, 2005, December 22*)*. Income from the CPP plan is taxable.

It is necessary to apply in order to start a CPP retirement pension. The age of beginning CPP pension permanently affects the pension amount. For each year less than 65 years of age on retirement, the amount of pension is decreased by 0.5% and each year older than 65 years of age on retirement increases the pension by 0.5%. After starting CPP pension, the amount that is earned does not affect eligibility; however, the individual cannot contribute further to the CPP program in order to raise their monthly pension amount (Human Resources and Social Development Canada, 2005, February).

Canada Pension Plan – Disability (CPP-D).

For workers who become disabled before 65, CPP offers a monthly income that includes a fixed amount plus an amount that is based on the amount contributed and the time period contributing. The average monthly benefit in 2005 was $758.86 and the maximum for 2006 is $1031.05 (Human Resources and Social Development Canada. (2006a). This is higher than the maximum (non-disabled) retirement pension. For this program, disability means that a mental or physical condition must be both "severe" and likely to be "prolonged" (including recurrence) resulting in regularly being incapable of "any substantially gainful occupation" (Department of Justice Canada. (2006, March 3d). The measure of "substantially gainful occupation" is defined as income equivalent to the maximum non-disabled CPP retirement benefit (currently $844.58 per month). Decisions about eligibility are made on a case-by-case basis by medical adjudicators who take into consideration medical evidence, vocational evidence and personal characteristics (Human Resources and Social Development Canada, n.d.). Benefits are also available for dependents of deceased disabled workers (Human Resources and Social Development Canada, 2005, February).

Old Age Security pension.

The Old Age Security Program provides income to individuals through the basic Old Age Security pension (OAS), the Guaranteed Income Supplement (GIS) and the Spousal Allowance. These are funded through general income tax revenue, are not taxable and are not based on employment history. The OAS is intended for citizens and legal residents who are at least 65 years of age and have resided in Canada at least 10 years since age 18. The maximum monthly benefit rate, currently $487.54, is based on 40 years of residency after age 18 with partial pensions being calculated on 1/40th of the pension payment per year of residency (Human Resources and Social Development Canada, 2006, June 29). Pension amounts are indexed quarterly based on the cost of living index and are subject to federal and provincial/territorial income tax (Department of Justice Canada, 2006, March 3f). Income of the pensioner determines how much of the OAS they are actually allowed to keep. Individuals who have a net income of more than $62,144 pay back a portion of the OAS. Those whose net income is $101,031 or above must return all of the OAS in "claw back" payments (Human Resources and Social Development Canada, 2006, June 29).

Guaranteed Income Supplement.

The Guaranteed Income Supplement (GIS) provides supplemental income for some low income pensioners. Eligibility is dependent on personal income for singles and joint income for persons in marriage or common-law relationships. Spouses who are separated involuntarily, such as occurs with institutionalization, are treated as single persons for purposes of these programs. Income must be under $14,352 for a single person (excluding income from OAS, GIS and the Spousal Allowance) to receive this benefit. GIS requires yearly reapplication based on the last year's income. Residence in

Canada for at least 6 months of the year is also required to receive the GIS. It is indexed quarterly based on the cost of living according to the consumer price index, but does not decrease with a drop in the cost of living (Human Resources and Social Development Canada, 2005, December 14). The GIS is not taxable income. The maximum current rate is $597.53 for a single person/month. For spouses, the rate is determined by whether their spouse is a pensioner or not with maximum rates ranging from $392.01-$597.53 per person per month (Human Resources and Social Development Canada, 2006, June 29).

The Spousal Allowance.

The Spousal Allowance is a benefit for those who are 60-64 years of age and in a marriage or common-law relationship with a pensioner who qualifies for the OAS and GIS. It is aimed at low income persons who are not yet eligible for OAS and GIS retirement benefits but whose spouse is a pensioner. It requires that the recipient has lived in Canada at least 10 years since age 18 and continues to live in Canada for over 6 months per year. Individuals must reapply each year because it is based on the previous year's income (or in cases of extreme change, estimation of present income). The maximum benefit is $879.55, which is the equivalent of OAS and the spouse of a pensioner GIS benefit rates. It is not taxable. Maximum income cannot exceed $26, 688 to receive this benefit. Reaching the age of 65, separation, divorce, or death of the pensioner spouse precludes receiving this benefit (Human Resources and Social Development Canada, 2006, March 09). If an OAS pensioner spouse dies, the remaining spouse is eligible for a maximum of $973.05 per month of Allowance for the Survivor benefits if they meet the eligibility requirements for the Allowance programs and their annual income is under $19,488. This Allowance for the Survivor benefit stops if the recipient establishes another spousal relationship or reaches the age of 65 (Human Resources and Social Development Canada, 2006, February 23a).

Federal income supplement.

The only federal income supplements available in Canada are for families of young children (see Canada Revenue Agency 2005, July 6).

Senior's Supplement in British Columbia.

The Senior's Supplement is governed by the Employment and Assistance Act and Regulations. This is a small top up of federal income assistance for low-income pensioners and spouses of pensioners to bring them to the minimum guaranteed income (British Columbia Ministry of Employment and Income Assistance, 2005, Oct 14). Eligibility is based on personal income for singles and spousal income for married couples. There is no need to apply for this benefit as it comes automatically for low income persons based on their income tax as filed. The current benefit for single persons and spouses of persons not receiving OAS/GIS/Allowance is $49.30 per month. Married spouses who are both receiving OAS/GIS each receive $60.25. Spouses who are only receiving the Spouse's Allowance receive $49.83 per month (British Columbia Ministry of Employment and Income Assistance, 2006, July 1b).

New Brunswick Senior's Benefit.

New Brunswick has a somewhat similar program, but with no guaranteed level of income. New Brunswick offers a $100 annual benefit per single senior living alone, or per couple to seniors who were residents on December 31st of the previous year and who receive either the GIS, Spousal Allowance, or Allowance for Survivors. In households where both spouses receive the GIS, each receives $100, as do each spouse if separated involuntarily (for example, by institutionalization) (New Brunswick Department of Finance, 2005).

Table 9 Comparison of Impacts of Pension Programs and Income Supplements by Region on Caregiver Costs
Key: CG=Caregiver, CR=Care Receiver, OOP costs=out-of-pocket costs

	Daughter Caregiver, Darla		Mother Caregiver, Mary		Husband Caregiver, Hal	
	Federal		Federal		Federal	
Old Age Security	▪CG not eligible (too young) ▪CR eligible if meets residency requirement, if so may ↓ CG OOP costs indirectly due to ↑ CR disposable income.		▪CG not eligible (too young) ▪CR not eligible (too young)		▪CG not eligible (too young) ▪CR not eligible (too young)	
Canada Pension Plan	▪CG not eligible (too young) ▪CR may be eligible (based on employment history), if so, may ↓ CG OOP costs indirectly due to ↑ CR disposable income.		▪CG not eligible (too young) ▪CR not eligible (too young)		▪CG not eligible (too young) ▪CR not eligible (too young)	
Canada Pension Plan-D	▪CG not eligible (not disabled) ▪CR is probably not eligible (due to definition of disability and age unless she applied before turning 65).		▪CG not eligible (not disabled) ▪CR may be eligible (if he has worked)		▪CG not eligible (not disabled) ▪CR not eligible (due to definition of disability)	
Guaranteed Income Supplement	▪CG not eligible (too young) ▪CR may be eligible, if so, may ↓ CG OOP costs indirectly due to ↑ CR disposable income		▪CG not eligible (too young) ▪CR not eligible (too young)		▪CG not eligible (too young) ▪CR not eligible (too young)	
Spouse's Allowance	▪CG not eligible (too young) ▪CR is not eligible (too old).		▪CG not eligible (too young) ▪CR not eligible (too young)		▪CG not eligible (too young) ▪CR not eligible (too young)	
	Cranbrook Area	Bathurst Area	Cranbrook Area	Bathurst Area	Cranbrook Area	Bathurst Area
Provincial Income Supplement Programs	▪CG not eligible (not a senior) ▪CR may be eligible (if income low enough,), if so, may ↓ CG OOP costs indirectly due to ↑ CR disposable income	▪CG not eligible (not a senior) ▪CR may be eligible (if receiving GIS), if so, may ↓ CG OOP costs indirectly due to ↑ CR disposable income.	▪CG not eligible (not a senior) ▪CR is not eligible (not a senior.)	▪CG not eligible (not a senior) ▪CR is not eligible (not a senior).	▪CG not eligible (not a senior) ▪CR is not eligible (not a senior.	▪CG not eligible (not a senior) ▪CR is not eligible (not a senior.

Analysis of Impacts of Pension Plans and Income Supplements

The results for this section are summarized in Table 9. None of the caregivers can directly benefit from public pension plans due to their young age. Whether Mary and Hal are receiving a pension from their previous employment (or, for Mary, perhaps from a widow's benefits) is not available from the data we have. However, they have been adults for over 40 years, so they may have accumulated some employment pension during that time. But not all Canadians have pensions available through their employment. As of 2001, less than 40% of Canadians belonged to a registered employment pension plan (Townson, 2001, p. 3). If they were not receiving some income we would expect them to describe themselves 'not employed' rather than 'retired.' Very few among the mother and husband caregiver group were disabled, so their early retirement raises questions about whether caregiving responsibilities played a part in their decision to retire. The high likelihood of 'significant' work disruption shown for husband caregivers tells an uncertain story for which we have inadequate details to make a decision. Many factors may influence the choice of time to retire (see Bidewell, Griffin, & Hesketh, 2006) not just caregiving.

Indirect impacts for Darla may decrease her out-of-pocket costs through pension assistance for her mother. The mother care receiver would be better off financially than persons on social assistance, because the total of old age assistance (OAS), guaranteed income supplement (GIS) and senior's supplements in either province is likely to be higher than the highest social assistance/disability assistance payments. She might also be eligible for some employment-related pension benefits such as Canada Pension Plan (CPP) if she has worked at times throughout her life. Senior pension and income supplement benefits do not require depletion of assets to qualify as does social assistance and the income cutoff for receiving senior benefits might allow her to have some employment if she becomes well enough to do so without losing all benefit. Even the maximum CPP payment is not high enough to require claw-back of OAS payments.

CPP-D might be a possibility for Mary's son but is not likely for either Darla's mother or Hal's wife, because eligibility is decided on a case-by-case basis considering medical, vocational and personal information and the definition of disability does not accommodate mood disorders well. While mood disorders may be severe and prolonged, the requirement of inability to earn at least $844.58/month might exclude both, because this amount can be earned with less than full time employment at minimum wage in either province ($6.70/hour in New Brunswick and $8.00/hour in British Columbia, see British Columbia Ministry of Labour and Citizen's Services, 2003; New Brunswick Post-Secondary Education and Training, 2006). Because CPP-D varies according to time worked and amount contributed before the disability, the benefit to persons who develop a lifelong illness early in life would be likely to be much less than those who develop an illness later in life, a differential effect that could cost some caregivers much more than others in out-of-pocket costs.

Provincial income supplements only apply to seniors so would only be likely to indirectly benefit Darla. Qualifying for this benefit would depend on the income level of her mother. Since mood disorders may begin at any point across the lifespan from childhood though old age, we have no way of predicting whether Donna would have additional pension income, such as CPP, besides the OAS/GIS that are not based on employment.

In conclusion, public pensions and income supplements are only useful to reduce the costs of those who care for seniors and result in no reduction of the costs of caring for adults who are not seniors. The only exception to this is CPP-D and the policy definitions make qualification very uncertain for persons with mood disorders, and inability to work at times throughout life may result in little benefit for those who could qualify.

3. Income tax deductions, credits and rebates.

Canada Revenue Agency impacts the income of all taxpayers through collection of federal income tax based on the Income Tax Act (Department of Justice Canada, 2004, August 31a and the Income Tax Regulations (Department of Justice Canada, 2004, August 31b) as well as the provincial and territorial income tax acts and regulations. Some deductions and credits may reduce the costs of caregiving directly through influence on the caregivers' disposable income while others reduce costs indirectly through influence on the amount of disposable income of care receivers. [3]

Tax deductions and credits work in different ways to affect disposable income. Tax deductions reduce the amount of income that is taxable. Examination of the income tax documents shows only one deduction, the disability supports deduction, that would benefit some caregivers of disabled persons and the impact would be indirect.

Disability Supports Deduction.

The disability supports deduction acknowledges that some persons with disabilities have extra costs required for working or going to school. It can be claimed only by those who are eligible for the Disability Tax Credit. Although this deduction allows for claiming the costs of many devices and services that apply to persons with physical disabilities, few apply to persons with mental disability.

The cost of a part- or full-time attendant, who may provide a variety of services including such services as meal preparation and housekeeping, shopping, banking and companionship can be deducted by the care receiver, if needed for school or work activities to occur. Only the care receiver is eligible to claim the attendant benefit for these purposes. The amount claimed for attendant services cannot exceed $10,000 per year ($20,000 in the year of the care recipient's death) paid to the attendant(s) who are at least 18 years old and are not the spouse of the care receiver (Canada Revenue Agency, 2005b). (Note: there are other ways to claim attendant expenses which are described following.)

Tax credits.

Tax credits reduce the amount of tax that is owed, thus increasing disposable income. This could impact caregivers through direct effects on their own income and indirect effects on the care receiver's income. Refundable tax credits, if in a higher amount than can be used to reduce the tax payable to zero, are payable to the taxpayer. Non-refundable tax credits may only be used to bring the tax payable amount down to zero and any excess costs may not be claimed. However, some tax credits are transferable. These may be transferred toward some other eligible taxpayer(s).taxes (Department of Finance Canada, 2006, March 16). Spouses have first priority for transferable tax credits. If the spouse of a person with a disability claims any portion of any non-refundable credit (other than medical expenses) from the care receiver, no other caregiver can claim transferable disability related credits.

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[3] Note: all tax documents are for 2005 since not all 2006 were available at the time of the study.

Non-refundable tax credits.

Although there are several tax credits that could benefit persons with low income or who are seniors, there are few that benefit either persons who have a disability or their caregivers. Of the non-refundable tax credits that could reduce caregiver costs, only the caregiver amount is intended specifically for caregivers. Other non-refundable tax credits that could reduce the costs of caregivers include the eligible dependent credit, the credit for infirm dependents 18 years of age and older, the disability amount and medical expenses. These can be claimed toward both federal and provincial taxes (with slightly different income eligibility criteria and tax benefits resulting for the two provinces).

For persons with high out-of-pocket costs, very few of the actual expenses incurred may count toward reducing taxes. There are maximum claim limits on each credit category. Amounts claimable for most transferable credits are reduced by all or a portion of the care receiver's income. The remaining amount for all non-refundable claims is multiplied by the lowest taxation rate in order to determine the amount of tax "already paid." For federal taxes this was 15%, for British Columbia 6.05% and for New Brunswick 9.68% as of the 2005 tax year. Unless otherwise specified, the tax information is based on (Canada Revenue Agency, *2006, February 28a, General income tax and benefits – 2005;* Canada Revenue Agency, 2006, January 4e, *5010-D Provincial Worksheet – British;* Canada Revenue Agency, 2006, January 4b, *5004-D Provincial Worksheet – New B;* Canada Revenue Agency, 2005, December 1c, *Federal* *worksheet 2005*). The amounts stated describe federal tax credits only. Provincial credits are quite similar in their calculation although the percentage counted toward taxes is higher in New Brunswick.

Caregiver Tax Credit.

Caregivers who lived with a care receiver who is their own or their spouse's child or grandchild, brother, sister, niece, nephew, aunt, uncle, parent, or grandparent who was a resident in Canada may claim a caregiver amount. The care receiver must be either over 65 or an adult dependent on the caregiver due to physical or mental infirmity (Canada Revenue Agency, 2006, January 1). This is of most benefit to those whose care receiver has little or no income, because, the caregiver amount that is claimable is reduced by the care receiver's income. The maximum federal credit that could be claimed for 2005 was $577.20, however, the dependent's income determines amount of credit. Care receiver income over $16,989 would reduce this benefit to zero for federal income tax in 2005. Single caregivers who claim the care receiver as their eligible dependent would not benefit from the caregiver amount, because the amount claimable for eligible dependent credit is also deducted from this credit (essentially canceling it out).

Eligible Dependent Credit.

This credit, which was formerly called the equivalent-to-spouse credit, can only be claimed by persons who were single, divorced, separated or widowed for any portion of the tax year and who supported certain family members in the claimant's home for a portion of the year. Support of children under 18, grandchildren, siblings, parents and grandparents of their own, their prior spouse(s), or by adoption qualifies for this credit. The maximum federal credit that could be claimed for 2005 was $1,101.60, however, the dependent's income determines amount of credit. Care receiver income over $8,079 would reduce this benefit to zero for federal income tax in 2005. This credit would not be available to any of the profiled 'high cost' caregivers.

Credit for Infirm Dependents 18 Years of Age and Older.

Caregivers wholly or partially supporting an adult child, grandchild, parent, grandparent, brother, sister, aunt, uncle, niece, or nephew of their own or their spouse who was mentally or physically infirm and dependent on others for assistance as attested by a medical professional may claim this credit. The care receiver must have lived in Canada at some point during the year to qualify. The maximum federal tax credit that could be claimed for 2005 was $577.20, however, the dependent's income determines amount of credit. Care receiver income over $9,308 reduces this benefit to zero for federal income tax in 2005. Single caregivers who claim the care receiver as their eligible dependent would not benefit from the infirm dependent credit, because the amount claimable for eligible dependent credit is also deducted from this credit (essentially canceling it out).

Disability Tax Credit.

Eligibility for this credit is based on the amount and duration of physical or mental impairment attested by a medical doctor or psychologist. The impairment must be severe enough to interfere with at least one activity of daily living at least 90% of the time. It must also occur or be expected to occur continuously for at least 2 years or recur in a manner that results in significant cumulative impact on ability to perform activities of daily living. Activities of daily living for the purposes of this credit include cognitive activities, seeing, hearing, speaking, eliminating and walking (Canada Revenue Agency, 2003, March 21, Subsection 118.4(1c)).

Credit not needed by the disabled person to reduce their own taxes to zero may be applied to the taxes of their spouse, or if not claimed by their spouse, to the taxes of another caregiver who is either:

A parent or grandparent caregiver (including in-laws) who claims the care receiver as an eligible dependent or infirm dependent (Canada Revenue Agency, 2003, March 21).

The parent, grandparent, child, or grandchild of a care receiver who could have claimed the care receiver as an eligible dependent or infirm dependent if the care receiver had no income (Canada Revenue Agency, 2003, March 21).

For those under 18, there is a special supplement in addition to those claimable for adults with disabilities. The maximum amount of credit this could offer to an adult person with disabilities and their caregiver in 2005 was $989.40 toward federal taxes.

Medical Expenses Credit.

There are two types of non-refundable Medical Expense Credits. The first is filed by a taxpayer for specified allowable medical expenses for themselves, their spouse and/or minor children. This credit is affected first by the *claimant's* income (with 3% of the claimant's net income up to a limit of $1,844 excluded before calculation of credit) and then by the amount of medical expenses which have a top limit. The maximum amount of federal income tax credit this could yield in 2005 was $750 per person.

The second type of medical expense credit can be claimed on behalf of other relatives including children over 18, grandchildren, parents, grandparents, siblings, aunts, uncles and nieces or nephews by blood or spousal relationship, who resided in Canada anytime during the year (Canada Revenue Agency, 2003, March 21). For each of these other relatives, the same calculation applies except that the credit amount is affected by the *dependent's* income and medical expenses up to a top limit. The maximum amount of federal income tax credit this could yield in 2005 was also $750 per person.

Medical expenses may be claimed for any 12 month period ending within the calendar year that the tax is filed. Allowable medical expenses are specified in the Income Tax Regulations and include such items as payment to medical personnel including attendants and psychologists; premiums for private health care plans and some drug plans; purchase, maintenance, repairs and supplies for devices or equipment to compensate for a disability; home renovations to remove barriers to accessibility; and transportation in some cases to obtain treatment (Canada Revenue Agency, 2003, March 21; Canada Revenue Agency, 2003, March 24a; Canada Revenue Agency, 2003, March 24b).

Refundable Medical Expense Supplement.

There is also a federal refundable medical expense supplement for low income working persons with high medical expenses. To qualify for the medical expense supplement, the claimant must be at least 18 by the end of the tax year, be resident in Canada throughout 2005, have earned income of no less than $2,857 and have claimed for one or both of the disability supports deduction or medical expenses. The maximum amount of federal income tax credit this could yield in 2005 was $750 per person, but this amount is affected by the combined income of both spouses (if applicable). If the combined income was more than $21,663 the credit is reduced from $750 and at $36,663 the claimant would be ineligible for this credit for federal tax in 2005 (Canada Revenue Agency, 2006, February 28a). There is no equivalent medical expense supplement credit for BC or NB taxes. Each of these provinces, however, has a provincial low-income tax reduction clause.

Provincial Low Income Tax Reductions.

Both provinces offer a further tax reduction to those who have low income. In British Columbia this is called the BC Tax Reduction. Persons whose income is $16,000 or less can claim the maximum amount of $360 deduction on their B.C. taxes. Above that income, the amount of reduction available decreases to zero at $26,000 (Canada Revenue Agency. (2005, December 1a; Canada Revenue Agency. (2005, December 1b). Persons in New Brunswick who have income $12,713 or less may claim the maximum of $468 reduction in New Brunswick tax. Above that income, the amount of reduction available decreases to zero at $22, 073 (Canada Revenue Agency. (2006, January 4a; Canada Revenue Agency, 2006, January 4b). In British Columbia this can only be used to reduce the low income persons' tax but cannot be transferred to the caregiver. In New Brunswick, it can be applied to reduce the spouse's tax after the low income person's tax is reduced to zero (Canada Revenue Agency, 2006, January 4b).

Table 10: Comparison of Impacts of Income Security Tax-based Programs on Caregiver Costs by Region

Key: CG=Caregiver, CR=Care Receiver, OOP costs=out-of-pocket costs

	Daughter Caregiver, Darla		Mother Caregiver, Mary		Husband Caregiver, Hal	
	Cranbrook Area	Bathurst Area	Cranbrook Area	Bathurst Area	Cranbrook Area	Bathurst Area
Disability Supports Deduction	▪ Federal and either province: CR probably not eligible (more applicable to physical disability than mental).		▪ .Federal and either province: CR probably not eligible (more applicable to physical disability than mental).		▪ Federal and either province: CR probably not eligible (more applicable to physical disability than mental).	
Caregiver Tax Credit	▪ Federal and either province: CG probably eligible. If so, ↑ CG disposable income, but may → little or no benefit depending on the income of the CR.		▪ Federal and either province: CG probably eligible. If so, ↑ CG disposable income, but may → little or no benefit depending on the income of the CR.		▪ Federal and either province: CG probably eligible. If so, ↑ CG disposable income, but may → little or no benefit depending on the income of the CR.	
Eligible Dependent Credit	▪ No CG Benefit. CG is not eligible to claim this (spouse in home).		▪ No CG Benefit. CG is not eligible to claim this (son is too old).		▪ No CG Benefit. CG is not eligible to claim this (spouse in home).	
Tax Credit for Infirm Dependents > 18 years	▪ Federal and either province: CG probably eligible. If so, ↑ CG disposable income, but may → little or no benefit depending on the income of the CR.		▪ Federal and either province: CG probably eligible. If so, ↑ CG disposable income, but may → little or no benefit depending on the income of the CR.		▪ Federal and either province: CG probably eligible. If so, ↑ CG disposable income, but may → little or no benefit depending on the income of the CR.	
Disability Tax Credit	▪ Federal and either province: CR may be eligible, if so, may ↑ CR disposable income → ↓ CG OOP costs. ▪ If any tax credits left after reducing CR taxes, CG may claim these to ↑ CG disposable income.		▪ Federal and either province: CR may be eligible, if so, may ↑ CR disposable income → ↓ CG OOP costs. ▪ If any tax credits left after reducing CR taxes, CG may claim these to ↑ CG disposable income.		▪ Federal and either province: CR may be eligible, if so, may ↑ CR disposable income → ↓ CG OOP costs. ▪ If any tax credits left after reducing CR taxes, CG may claim these to ↑ CG disposable income	
Medical Expenses Credit	▪ Federal and either province ↑ CG disposable income.		▪ Federal and either province ↑ CG disposable income.		▪ Federal and either province ↑ CG disposable income.	
Refundable Medical Expense Supplement	▪ Federal and either province CR may qualify if income and expenses are high enough, if so, ↑ CR disposable income → indirect ↓ CG OOP costs.		▪ Federal and either province CR may qualify if income and expenses are high enough, if so, ↑ CR disposable income → indirect ↓ CG OOP costs.		▪ Federal and either province CR may qualify if income and expenses are high enough, if so, ↑ CR disposable income → indirect ↓ CG OOP costs.	
Provincial Low Income Tax Reduction	▪ Either province: CR may be eligible, if so, may ↑ CR disposable income → indirect ↓ CG OOP costs.		▪ Either province: CR may be eligible, if so, may ↑ CR disposable income → indirect ↓ CG OOP costs		▪ Either province: CR may be eligible, if so, may ↑ CR disposable income → indirect ↓ CG OOP costs	

Analysis of Impacts of Tax Deductions, Credits and Rebates.

The results for this section are summarized in Table 10. For direct reduction of the caregivers' costs, the three non-refundable credits that could apply are not likely to yield much, if any, reduction. The profiled 'high cost' caregivers all might qualify for Caregiver Tax Credit because their relationships, co-residence with the care receiver and age and mental infirmity of the care receiver meet eligibility criteria. None of them would qualify for the Eligible Dependent Credit due to either having a spouse or the relationship with the care receiver not meeting criteria. All might qualify for Credit for Infirm Dependents 18 Years of Age and Older based on their relationships and the age and mental infirmity of the care receiver. All of these three credits associated with disability are reduced by the income of the care receiver and the amounts of care receiver income at which the benefits cease is low. The low income cutoff (before tax) (LICO) for one person living in a small urban area such as these two chosen areas is $16,273 (Statistics Canada, 2006). The income cutoff for benefits for the Caregiver's Amount is slightly more than the low income cutoff, but the benefit goes to zero for the Eligible Dependent Credit if the care receivers earn less than half of the LICO, and reduces to zero for the Infirm Dependent Credit if they earn slightly over half of the LICO. Such low income cutoffs result in little reduction of high costs associated with disability and care for persons whose income is low enough to be likely to require much economic help from the caregiver for purchases of the goods and services they need.

All of the profiled 'high cost' caregivers would qualify to claim these, which could lower their taxes. Several of the items listed in the Income Tax Act (Canada Revenue Agency, 2003, March 21) as claimable have been documented as high cost items for caregivers of persons with mental illness: costs of medical personnel, psychologists, attendants, medications and transportation for treatment out of the area. There are limits, however, on the amount that can be claimed ($750 maximum credit) and this also is reduced by a portion of the care receiver's income.

Concerning indirect reductions in caregiver costs by any increase in the care receiver's disposable income through tax deductions, only the Disability Supports Deduction could apply. Program eligibility criteria for the Disability Supports

Deduction rules out all of the 'high cost' care receiver profiles, because they would have to be either working or going to school and to need an attendant for these actions to occur. For these care receivers, however, when they are least able to work or go to school is when they would be most likely to need an attendant, such as someone to stay with them if they are likely to do harm to themselves or others. Claims for other devices and services that are a part of this deduction are unlikely because they are designed for physical rather than mental disabilities.

Refundable credits for medical expenses may provide some indirect reduction of caregiver costs by increasing the care receiver's disposable income. It is uncertain whether either Donna or Helen would qualify for the disability credit. The requirement of interference with an activity of daily living at least 90% of the time might rule them out if their mood disorder is episodic. If they do qualify, however, the refundable medical credit requires that the care receiver have at least $2,857 in income and sufficient medical expenses to claim this credit. The upper limit of income for eligibility for this benefit for one person without a spouse is not clearly stated in the tax documents.

Low income reductions may also increase care receiver disposable income, depending on whether the care receiver's income is below $26,000 in British Columbia or $22,073 in New Brunswick. This program could reduce the care receiver's taxes in either province, but leftover credits can only be transferred in New Brunswick to reduce spouse's taxes.

In conclusion, tax benefits offer little reduction of caregiver costs and can vary widely based on the age, relationship and disability status of the care receivers.

Summary of Impacts of Income Security Domain Programs

In conclusion, there are several income security programs that could reduce caregiver costs temporarily and to a small degree, but most offer little, if any, reduction of the costs of these 'high cost' caregiver profiles. Caregiving does not make one eligible for social assistance (except for spouses in British Columbia). Forgoing employment to give care in either province would be risky because of higher unemployment rates than the Canadian average. Their age does not allow a pension, but the public programs that were examined do not support caregiving as an occupation.

Even disability programs are not well-suited to offer income security to adults with mental illness. The disability definitions for everything from income assistance, to employment training, to tax benefits vary widely. The programs are often aimed at physical rather than mental disorders, at permanent rather than episodic disability and at working toward complete independence rather than supportive interdependence.

Indirect reduction of out-of-pocket caregiver costs could occur through income security programs for persons with disabilities as, in principle, they would be more likely to purchase their own goods and services if they have adequate income. Flexibility seems to be missing and, yet, to be very necessary for persons who care for someone with mental illness. There is no partial support either to help the care receiver to become well or to help the caregiver to give care.

A variety of other benefits that can decrease out-of-pocket costs for caregivers are tied to persons receiving social assistance or disability assistance. The social assistance programs deplete assets, offer very low supplement and make it very hard for persons with mental illness to leave social assistance, because of inadequate opportunities to gain (or regain) resources and because they offer so many necessary medical benefits that are expensive to purchase.

Senior persons with mental illness are likely to have more income assistance than working age persons with mental illness, because even the minimum Old Age Security pension, Guaranteed Income Supplement and other seniors' benefits are greater than disability assistance rates in either province (and much greater than the non-disabled social assistance rates). Age and disability status of the care receiver strongly influences costs for the caregiver.

Caregivers' costs can be reduced by some tax benefits, but actual reductions in costs are small, largely because so many of them are determined by the care receiver's income and it need not be large to eliminate benefits. Very little policy is focused on caregivers and accessing some benefits rules out others. Although many of the tax benefits are dependent on relationship and living together with the care receiver in order to qualify, acknowledgement that they are giving care and incurring expenses offers little in the way of reimbursement of those expenses.

Health Domain Scan

Health programs may impact the costs of all of the caregivers because mental illness is a health concern that touches many areas of life. Persons with mental illness have potential for any of the health concerns of any other adults as well as additional risks and concerns related to their illness and treatment. Costs of treatments may be a major source of economic costs of caregiving.

Health program funding is jointly shared by federal and provincial governments (Department of Justice Canada, 2006, March 3a), but provision and administration of health programs occurs at the regional level through some form of regional health authority. Health programs that were reviewed included basic physician and hospital services, allied health services, drug plans, home care programs and mental health programs. Separate mental health and physical health services exist, in some cases supplying the same or similar benefits but with different eligibility criteria. Therefore, services offered through each program are described briefly within the larger program umbrella of home care programs and mental health programs. Programs that might reduce transportation costs for caregivers associated with obtaining treatment for the care receiver were also examined and are presented within the health domain, since these were, in some cases, coordinated by a regional health authority or were a benefit related to health status.

1. Basic physician and hospital services.

Basic physician and hospital services in British Columbia.

British Columbia's Medical Services Plan (MSP) provides coverage for legal permanent residents and some persons on study and/or work permits as well as legal refugees. They are eligible after a waiting period including the remainder of the month they begin residing in British Columbia plus two additional months. To be eligible, physical presence in British Columbia at least 6 months of the year is required. There is a charge of $54 per month per person. Families pay less per person than individuals; however, family, in this case includes only spouse (legal, cohabitating in a spousal relationship, heterosexual or homosexual) and children (single and not cohabiting in a spousal relationship, under 19, or 19-24 and in full-time school attendance, and being supported by their parent(s)) (British Columbia Ministry of Health, 2005, October 3a). British Columbia premium costs may be subsidized on a sliding scale either regularly or temporarily for three month periods of financial difficulty depending on net adjusted income after deductions for age, family size and disability. Subsidies range from 20% for a net adjusted income level of $28,000 to 100% subsidy if income is less than $20,000 (British Columbia Ministry of Health, 2005, October 3a).

Benefits of the MSP include medically required hospital and outpatient treatment, diagnostic tests (when performed in approved facilities), required (described as non-elective, non-cosmetic) surgical procedures including dental and podiatry procedures which are required to be conducted in a hospital and most physician services (British Columbia Ministry of Health, 2005, October 3b). Additional benefits include eye examinations for medical reasons and routine eye exams for those under 18 and over 65.

Basic physician and hospital services in New Brunswick.

New Brunswick's basic medical program is called Medicare. After a three month waiting period, this program provides hospital and physician services to all legal residents who make their permanent and principal home in New Brunswick. There is no premium charge for Medicare coverage, but registration is mandatory and presence in New Brunswick is important to continue eligibility (New Brunswick Health , n.d.g).

Essential hospital services including medical and surgical services, nursing service, supplies and allied health care in hospitals as well as diagnostic services and physician's services are covered by Medicare. No elective procedures are covered, including surgeries for removal of skin lesions unless they are suspected to be malignant (New Brunswick Health, n.d.g). For services that have been approved to be provided outside of New Brunswick, Family and Community Services Health

Services/Hospital Program will assist their clients if "The cost of the service(s) exceeds the fees paid by New Brunswick Medicare" (New Brunswick Health, n.d.e, p. 1).

Some basic health services also are offered without charge in the home through the Extra-mural Program. Since 1981, New Brunswick has been operating the Extra-mural Program (EMP) which was designed to function as a hospital without walls. The intention of the Extra-mural Program was to facilitate early hospital discharge and postponement of hospitalization by providing healthcare services in the client's own home that would otherwise be available in a hospital. The stated goal was not to replace family care but to supplement client self-care, informal and formal care (New Brunswick Health, 2003, April).

There are no charges for medical supplies used in the home connected with Extra-mural Program acute care in the home. Services by nurses, respiratory technologists, physiotherapists, occupational therapists, speech-language pathologists, dieticians and social workers are provided free of charge (Atlantic Health Sciences Corporation, n.d.d); however, these are on a visit basis for particular care tasks rather than providing continuous care.

2. Allied health services.

Allied health services in British Columbia.

Some persons may be eligible for supplementary benefits: limited subsidized amounts of $23 per visit up to 10 visits per year for chiropractic care, massage and physiotherapy, naturopathic care, non-surgical podiatry services, psychologist and counselor's fees. Persons eligible for these supplementary benefits include those with low incomes, receiving income assistance, inmates in provincial correctional facilities, residents in long-term care facilities, refugees, medically dependent children and those registered with MSP as mental health clients (British Columbia Ministry of Health. 2005, October 3b). However, glasses, hearing aids, dental work (other than that required to be performed in a hospital) and dentures are not included benefits.

Allied health services in New Brunswick.

Chiropractic treatment, massage therapy, naturopathic care, vision care, physiotherapy and psychologist's fees are all excluded from Medicare coverage in New Brunswick (except fees for psychologists employed by Mental Health Centres). Persons who receive social assistance, or are blind, deaf, disabled, a child in government care, or a person in a long-term care institution (who does not have a spouse to pay for these costs) may qualify for these supplementary benefits as well as some assistance with costs of dental care (New Brunswick Family and Community services, n.d.b), eyeglasses (New Brunswick Family and Community Services, n.d.d), hearing aids (New Brunswick Family and community services, n.d.c), nursing services and some prescription medications under the Family Income Security Act (New Brunswick, 2005, September 1). However, disability is defined for these programs to mean that their impairment "is likely to continue indefinitely without substantial improvement and that causes the person to be severely limited in activities pertaining to normal living" (New Brunswick, 2005, September 1, p. 1).

If the care receiver does qualify, the amounts allowed for allied health services are very low and would be more a subsidy than a reimbursement. For instance, full mouth surgical removal of 22 or more teeth is not to exceed $186.00 (New Brunswick, 2002, June 30, p. 14). Careful reading of the requirements would be required to avoid making choices that rule out some benefits. For instance, buying glasses frames that have a wholesale cost greater than $17.00 can rule out reimbursement for the dispensing fee (New Brunswick, 2002, June 30, *p. 31*). User fees are charged for most of these programs, including $4.00 per use of an entitled service for adults who receive social assistance up to a $250 per year limit per participant and their dependents and pre-approval through separate approval boards is required for many services (New Brunswick, 2002, June 30).

3. *Drug plans.*

Drug plans in British Columbia.

The Fair Pharmacare program has been in place for all British Columbia residents who qualify for MSP since May 1, 2003. Annual deductibles range from 0-3% of the net family income. Annual maximums payable are 1.25-4% of their net family income. Clients are responsible for 100% of the costs until the deductible amount is reached followed by a co-payment of 30% (25% for seniors) of the cost of the prescription until their annual maximum is reached (see, British Columbia Ministry of Health, n.d.b). Thereafter, the Pharmacare program pays 100% of prescription costs for the rest of the year.

Pharmacare also has several special plans. Full funding is available for persons in long-term care facilities, on income assistance, who are HIV positive and children in the Ministry of Children and Family Development at home program. Some medications are provided free of charge for persons who have cystic fibrosis, are in palliative care, or are HIV positive. Persons registered with a mental health service centre may qualify for full funding for most mental health medications and side effect controlling medications due to clinical and financial need (British Columbia Ministry of Health, 2006, June 21d). Persons who obtain some of their medications free of charge based on a health condition are also eligible for Fair Pharmacare coverage for remaining medications at their income-based rate.

Drug plans in New Brunswick.

The New Brunswick prescription drug plan *(NBPDP)* does not cover all New Brunswick Medicare eligible residents (New Brunswick Health, 2002, December 31). To receive drug benefits, a person must be a senior, on social assistance, a child in care of the Ministry of Health or with special needs, or have a condition requiring special medications, such as: cystic fibrosis, multiple sclerosis, solid organ transplant, or HIV positive status. Mental illnesses are not listed as conditions of eligibility for benefits. For those who qualify, the co-payment cost per prescription varies with annual limits ranging from $250 per family unit to no limit. For seniors to qualify, they must be either receiving GIS or have an income of $17,198 or less for a single senior. The senior co-payment is $9.05 with a $250 annual limit for seniors on GIS or $15 co-payment for those who qualify because of their low income. The co-payment for those on social assistance is $4 per prescription for adults with a $250/family unit annual ceiling. Most of the drug plans in New Brunswick charge a $50 yearly user fee, although the plans for seniors, persons on social assistance and nursing home residents do not (see New Brunswick Health, n.d.h; New Brunswick Health, n.d.i; New Brunswick Health, n.d.j).

4. Home care provision in Canada.

The Canada Health Act (Department of Justice Canada, 2006, March 3a) does not include provision of home care or other long-term care services in the home or community. Provincial governments address the need for home and community care in a variety of ways through the health regions (Home Care and Mental Health Policy Forum Advisory (Planning) Committee, 2006).

Both British Columbia and New Brunswick employ a single entry strategy for community and long-term care programs, mental health and addiction programs and social assistance and employment programs. This means that clients may enter any one of these programs and they will be assessed and referred to the other programs for services deemed to be necessary. Assessment information is shared among the programs. This could be especially useful when persons with mental illnesses develop physical illnesses as well.

Home care services programs in British Columbia.

Community and Long-term Care administers a variety of services that are intended to support clients' independence, prevent or shorten hospital time and provide for care needs at the end of life through assisting, rather than replacing family and friend care. Nursing services, case management and rehabilitation services are supplied without charge to clients who have a need for either acute or continuing physical care. Home support services, respite, adult day programs and palliative care services are also available based on assessed need and may be subsidized on a sliding scale based on income of care receivers who are 19 years or older, legally residing in British Columbia for the requisite time (which varies according to service) and who cannot function independently due to chronic health problems or end-stage illness attested by a physician (British Columbia Ministry of Health, 2004, p. 21). Meals On Wheels are also available for persons not able to prepare their own meals at $6.50 per meal regardless of income level; however, they are only delivered 3 times per week (British Columbia Interior Health, 2005, October13b).

Home care programs in New Brunswick.

Since the inception of the Extra-mural Program (EMP) in 1981, provision of long-term services in the community has been transferred to a collaboration of EMP, Mental Health Services and Family and Community Services (New Brunswick Health, 2003, April). In response to a referral from a physician (or designate) with admitting privileges for the region, the Extra-mural Program provides necessary health care services that can safely be provided in the care receiver's home (Atlantic Health Sciences Corporation, n.d.b). Rehabilitation services may also be obtained through self-referral or referral from another agency, family members, or friends.

Persons of all ages who are currently registered for New Brunswick Medicare may qualify for Extra-mural Program services based on their needs and financial assessment. Allied health professional services of nurses, registered dietitians, respiratory therapists, occupational therapists, physiotherapists, speech language pathologists and social workers (where funded) are provided free of charge. These services are intended to provide acute care, palliative care, home oxygen program, long-term care assessment and rehabilitation services in the home (New Brunswick Health 2003, April).

Additional home supports, such as homemaker service, meal preparation and Meals On Wheels are provided on a sliding scale (largely through third-party nongovernmental organization contracts) (Atlantic Health Sciences Corporation, n.d. a) according to the fees determined through a combined needs assessment. These services

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are primarily limited to persons with physical disability or illness. Persons with mental illness are referred to Addiction and Mental Health Services for case management and referral for more specialized services. Adult day programs are separated for various groups with special needs and costs are assessed according to combined income.

5. *Mental health and addiction services.*

Mental health services programs in British Columbia.

Most mental health and addiction services are provided through Mental Health Centres throughout the province, which offer case management, counselling and crisis intervention free of charge (weekdays and Saturday 0830-1630) (British Columbia Interior Health, 2005, October 13d). Presently, only the crisis line, funded by Mental Health Services and staffed by trained volunteers, is available for crisis situations when the Centre is closed (Crisis Intervention and Suicide Prevention Centre of British Columbia, 2006a). Clients may be referred by medical professionals or self-referred on a drop in basis. Although some rehabilitation activities take place in the home, most counselling and rehabilitation activities take place in the Centre.

Mental Health Services has a respite budget and a home support budget apart from that of Community and Long-term Care and offers some home support services (British Columbia Interior Health, 2005, October13a). Respite for mental health may be available to caregivers, usually through temporary placement of the care receiver in a Family Care Home. The cost of such respite is on a per diem basis. This fee is calculated based on the income of the care receiver unless they are in a spousal relationship, in which case, the per diem cost is based on their combined incomes.

Rehabilitation and home support, including homemaking services from Mental Health Services, is offered in the home by home support workers who encourage development of life skills by working side by side with the care receiver on household tasks. Home support may have fees assessed on a sliding scale based on income of the care receiver, or, if married, the combined incomes. Meals On Wheels service is also available to persons with mental illness at a set rate per meal (British Columbia Interior Health, 2005, October13b).

The Kootenay Clover Clubhouse is operated by Mental Health Services and staffed by Interior Health employees. The Clubhouse charges no fees except those associated with outside recreational outings and offers programs in the daytime to promote life skills, relationship skills and preparation for employment. It is open all days except Christmas.

Mental health services programs in New Brunswick.

Mental health services may be obtained in New Brunswick through 13 Community Mental Health Centres (CMHC) (one of which is in Bathurst) (New Brunswick Health, n.d.b), 22 other combined social service provision locations, general hospital psychiatric units and psychiatric hospitals. Services for the Elderly is one of the mental health services programs in New Brunswick. It is intended to provide services to care receivers with both significant mental and physical problems (and may include younger persons with complex physical and mental problems) (New Brunswick Health, n.d.l). Non-profit organizations and consumer-run programs provide some mental health services and are listed on the government of New Brunswick website as service providers. The Crisis Line is one such agency manned by trained volunteers who assess and refer to other agencies 24 hours a day (Government of New Brunswick, 2002).

CMHCs operate 8:30 a.m. to 5:00 p.m. on weekdays and provide crisis intervention services on evenings and weekends. Offered services for adults include: assessment, a variety of interventions and treatments provided by nurses, psychologists, social workers and counselors, consultation with other agencies concerning care, crisis intervention, community support and rehabilitation (New Brunswick Health, n.d.b). Although some home visits are made as necessary, most activities take place in the CMHC during daytime weekday hours.

All New Brunswick residents are eligible to access services either with a health professional referral or by their own request through visiting a CMHC. There are no fees for the programs offered by the CMHC for those with a New Brunswick Health Card. However, according to assessed needs, CMHCs may refer clients to Family and Community Services for respite services, homemaking services and Meals On Wheels, all of which have fees, based on the care receiver's income and assets or, if in a spousal relationship, the combined income and assets of the couple (New Brunswick Family and Community Services, 2006, April 1).

Phone contact with Family and Community Services (August 18, 2006) to clarify some questions left unanswered by the web pages added the information that respite is rarely arranged for mental health client caregivers and, if so, is usually arranged through payment of someone familiar to the recipient, a friend or other person who is not a relative for a certain number of hours. Family members cannot be paid to do this. Homemaking is available mainly for persons with physical disabilities and developmental disabilities as well as mental illness.

The intention of Mental Health Services in New Brunswick is not to replace family care but to "strengthen natural support networks" (p. 5), work with community resources and provide assistance "only as long as necessary in order to enable people to take charge of their lives again, thus avoiding dependency on the formal system" (New Brunswick, n.d.b, p. 5).

6. Medical transportation.

The federal government offers an excise tax refund of $0.015 per liter or $0.0015 per kilometer, on the written certification of a medical practitioner, to persons who cannot safely use public transportation, however, only those who have mobility problems are eligible (Canada Revenue Agency, 2000, February 29).

The federal government has declared a new non-refundable tax credit for monthly and yearly public transit passes which allows for a partial remuneration for expense of transportation (in tax credit). This tax credit can be fully or partially transferred from someone in a spousal relationship and from children under 19 years of age (Canada Revenue Agency, 2006, June 19).

Medical transportation in British Columbia.

For local transportation, British Columbia Transit offers a free annual local bus pass to persons who receive federal Guaranteed Income Supplement, federal Spouse's

Allowance, or British Columbia income assistance for persons under 60 years old and persons with disabilities (British Columbia Transit, 2006a). If none of these conditions apply, British Columbia Transit supplies frequent service throughout the city of Cranbrook at $1.75 per trip for adults and $1.50 for seniors. HandyDART service is available to persons with disabilities for a fee of $2.00 for a passenger and no charge for attendants (British Columbia Transit, 2006b). This service is intended to provide both regularly scheduled and irregular transportation for those with disability that precludes use of conventional transit service without assistance. Neither of these programs specifies mobility problems for eligibility.

For outlying areas around Cranbrook, a twice weekly service is offered through a partnership of Interior Health and the British Columbia Transit for medical appointments in Cranbrook (and, as available seating permits, other activities) for $2.00 each way (British Columbia Interior Health, 2005, December 30).

Medical transportation in New Brunswick.

A transit test project was conducted in Bathurst June 6 to March 31, 2006 charging $3 one way or $100 per month. This test project was, however, ended early due to inadequate funding to continue (Bathurst Sustainable Development Organization, 2006, May 20). This was the only public transit in Bathurst.

Table 11: Comparison of Impacts of Health Programs by Region on Caregiver Costs
Key: CG= Caregiver, CR=Care receiver OOP=out-of-pocket cost

	Daughter Caregiver, Darla		Mother Caregiver, Mary		Husband Caregiver, Hal	
	Cranbrook Area	Bathurst Area	Cranbrook Area	Bathurst Area	Cranbrook Area	Bathurst Area
Basic physician/ hospital services	▪ May ↑ CG OOP costs for medical services plan fee depends on CR income after deductions for age, family size and disability) ▪ ↓ CG OOP costs for supplied goods and services (more comprehensive than NB	▪ ↓ CG OOP costs for supplied goods and services (less comprehensive than BC) ▪ ↑ CG unpaid labour, ↑ OOP costs and ↑ employment disruption if CR acutely ill & using Extra-mural Program	▪ May ↑ CG OOP costs for medical services plan fee (depends on CR income after deductions for age, family size and disability) ▪ ↓ CG OOP costs for supplied goods and services (more comprehensive than NB)	▪ ↓ CG OOP costs for supplied goods and services (less comprehensive than BC) ▪ ↑ CG unpaid labour, ↑ OOP costs and ↑ employment disruption if CR acutely ill & using Extra-mural Program	▪ May ↑ CG OOP costs for medical services plan fee (depends on joint CG & CR income after deductions for age, family size and disability) ▪ ↓ CG OOP costs for supplied goods and services (more comprehensive than NB	▪ ↓ CG OOP costs for supplied goods and services (less comprehensive than BC) ▪ ↑ CG unpaid labour, ↑ OOP costs and ↑ employment disruption if CR acutely ill & using Extra-mural Program
Allied health	▪ ↓ CG OOP costs for chiropractic, massage, naturopathic care, physiotherapy, non-surgical podiatry, psychologist & counselor (if registered with mental health (but has user fees) ▪ ↑ CG OOP costs for dental, vision, hearing	▪ May have ↓ CG OOP costs for chiropractic, massage, vision, & naturopathic care, physiotherapy and psychologist's fees if low enough income—amount not specified (but has user fees) ▪ ↓ CG OOP costs for dental, glasses, hearing aids (but user fees)	▪ ↓ CG OOP costs for chiropractic, massage, naturopathic care, physiotherapy, non-surgical podiatry, psychologist & counselor if registered with mental health (but has user fees) ▪ ↑ CG OOP costs for dental, vision, hearing	▪ May have ↓ CG OOP costs for chiropractic, massage, vision, & naturopathic care, physiotherapy and psychologist's fees if on social assistance (but has user fees) ▪ ↓ CG OOP costs for dental, glasses, hearing aids (but user fees)	▪ ↓ CG OOP costs for chiropractic, massage, naturopathic care, physiotherapy, non-surgical podiatry, psychologist & counselor if registered with mental health (but has user fees) ▪ ↑ CG OOP costs for dental, vision, hearing	▪ May have ↓ CG OOP costs for chiropractic, massage, vision, & naturopathic care, physiotherapy and psychologist's fees if joint income is low enough—amount not specified (but has user fees) ↓ CG OOP costs for dental, glasses, hearing aids (but user fees)

Table 12: Comparison of Impacts of Health Programs by Region on Caregiver Costs (continued)
Key: CG= Caregiver, CR=Care receiver OOP=out-of-pocket cost

	Daughter Caregiver, Darla		Mother Caregiver, Mary		Husband Caregiver, Hal	
	Cranbrook Area	Bathurst Area	Cranbrook Area	Bathurst Area	Cranbrook Area	Bathurst Area
Drug plans	▪ ↓ CG OOP cost (free mental health drugs) but 25% co-payment for any other drugs (senior rate)	▪ ↓ CG OOP cost (but with senior co-payment)	▪ ↓ CG OOP cost (free mental health drugs) no co-payment for other drugs if CR is on social assistance.	▪ May have ↓ CG OOP cost if on social assistance, but with co-payment	▪ ↓ CG OOP cost (free mental health drugs) no co-payment for other drugs if on social assistance.	▪ May have ↓ CG OOP cost if on social assistance, but with co-payment
Home care	▪ Little effect unless CR is physically ill	▪ Little effect unless CR is physically ill	▪ Little effect unless CR is physically ill	▪ Little effect unless CR is physically ill	▪ Little effect unless CR is physically ill	▪ Little effect unless CR is physically ill
Mental health	▪ ↓ CG OOP costs for transportation (senior reduction on buses) ▪ ↓ CG OOP costs for counselors ▪ ↑ OOP costs for home support, respite, unless CR income low enough (amount not stated)	▪ ↑ CG OOP costs for transportation ▪ ↓ CG OOP costs for counselors ▪ ↑ CG OOP costs for home support, respite, adult day programs unless CR income low enough (amount not stated)	▪ ↓ CG OOP costs for transportation (bus pass if on social assistance) ▪ ↓ CG OOP costs for counselors ▪ ↑ CG OOP costs for home support, respite, unless CR income low enough (amount not stated)	▪ ↑ CG OOP costs for transportation ▪ ↓ CG OOP costs for counselors ▪ ↑ CG OOP costs for home support, respite, adult day programs unless CR income low enough (amount not stated)	▪ ↓ CG OOP costs for transportation ▪ ↓ CG OOP costs for counselors ▪ ↑ CG OOP costs for home support, respite, unless CR joint income low enough (amount not stated)	▪ ↑ CG OOP costs for transportation ▪ ↓ CG OOP costs for counselors ▪ ↑ CG OOP costs for home support, respite, adult day programs unless CR joint income low enough (amount not stated)
Medical transportation	▪ ↓ CG OOP costs for attending treatment services (seniors have a greater ↓ than younger adults)	▪ ↑ CG OOP costs for attending treatment services	▪ ↓ CG OOP costs for attending treatment services	▪ ↑ CG OOP costs for attending treatment services	▪ ↓ CG OOP costs for attending treatment services	▪ ↑ CG OOP costs for attending treatment services

Analysis of Impacts of Health Programs

Basic physician and hospital services plans in both provinces provide essential treatments, thus reducing out-of-pocket expenditures for goods and services for basic health care. British Columbia's definition of 'essential' was more comprehensive than New Brunswick's which could result in higher costs for caregivers in New Brunswick if the care receiver needs services such as dental surgery. The monthly fee for the medical services plan in British Columbia could raise caregiver out-of-pocket costs unless the care receiver's adjusted annual income is below $20,000. If the care receiver is on either social assistance (whether considered disabled or not) or public old age pension (unless they have employment related pension income), this is not likely to be a cost for the caregivers. We do not know any of the care receiver's employment histories, but we do know that they all have long-term illnesses (for which care has been received for at least 8 years), so the likelihood of the illness interfering with employment of the care receiver would be high. Hal may not be able to benefit from the premium subsidization depending on the amount of their combined incomes. Darla's and Mary's care receivers are evaluated on only their own income.

Although both provinces supply health-related goods and professional services without charge inside the hospital, New Brunswick's Extra-mural Program may increase all three types of costs for caregivers if they receive acute care services for any physical illnesses at home. Although there are no charges for medical supplies or visits of allied health professional services in the Extra-mural Program, medications, food and basic caregiving that would be provided free of charge in hospitals are not covered in the home resulting in higher out-of-pocket costs. Caregiver unpaid labour costs and employment-related costs (for employed caregivers) would be increased by the Extra-mural Program, because basic caregiving is not supplied around the clock as in the hospital.

Both provinces have programs that subsidize the costs for a variety of allied health services including psychologists and counselors, which could reduce caregiver out-of-pocket costs. All of the caregivers could have reduction of the costs of these services in British Columbia through the care receiver being registered with Mental Health Services, but the available subsidies are only a small part of the costs for these services and are limited to 10 visits. Similarly, reduction in costs for allied health services is available in New Brunswick if any of the care receivers qualifies as disabled or is on social assistance, but fees are involved. It is uncertain whether Donna or Helen would qualify as disabled with a mood disorder using the New Brunswick definition, especially if their illness course is episodic and they are able to perform their own personal care.

The needs for costly equipment such as glasses, hearing aids, dental work and dentures that tend to accompany even healthy aging can result in costs that may be paid by the daughter caregiver and perhaps the spouse caregiver if the care receiver cannot afford them. In British Columbia, there is no assistance with these costs, except for eye examinations for medical reasons and for children and seniors. New Brunswick offers limited assistance with these costs, but only to those who are disabled or on social assistance, and there are still user fees involved. The requirement for pre-approval of some of these services could increase the unpaid labour costs of caregivers for submitting paperwork and advocating for their family member or friend. Mary, however, is more likely to have indirect reduction of these costs because schizophrenia would be more likely to be considered a disability in either province.

The costs of medication could vary widely depending on the drug plans that are available. The two provincial programs would result in very different costs for caregivers. Although the cost of the psychiatric medications and side effect medications may be free for all three of the care receivers in British Columbia (if there is clinical and financial need), the co-payments for any other medications that are necessary may add up to substantial cost for any of the caregivers even with Fair Pharmacare. Financial hardship could occur at the beginning of each year as the caregiver must pay 100% of their own medications as well as perhaps paying 100% of the costs of the care receiver's medication until their deductible is reached. The 25% co-payment for seniors that has to be paid until the yearly maximum is reached would increase Darla's out-of-pocket costs, as would the 30% co-payment required for non-seniors for Mary's and Hal's costs.

In New Brunswick, the prescription drug plan would probably cover two of the 'high cost' care receivers but none of the caregivers. If Mark qualified for social assistance, his low rate of assistance income might mean that the co-payment of $4 for each prescription up to a limit of $250 could become the cost of his mother, Mary. For Donna, having a required $15 co-payment could yield costs that Darla pays. It is uncertain whether Helen would qualify for the drug plan as she may not be considered disabled and would not be likely to be on social assistance due to her husband's income, so Hal may pay the full price of her medications.

Both regions provide a similar set of health professional services in the home through home care services and both charge fees on a sliding scale for home support services, respite, adult day care, and Meals On Wheels based on the income of the care receiver (and their spouse, which for Hal could mean more costs). Documents for the two home care programs primarily emphasized care of persons with physical illnesses and palliative care, so little benefit is likely for any of the three caregivers unless the care receiver becomes physically ill or physically disabled.

Mental health services also were similar for the two regions with free professional services through Mental Health Centres as well as daytime socialization and rehabilitation activities provided at no cost through the Centres. Home support, respite and Meals On Wheels were similarly offered on a sliding scale based on financial assessment of the income of the care receiver (and their spouse, which for Hal could mean more costs). No information was found in the documents to determine whether the sliding scale differs for the two regions or the lowest income level required to qualify for either home care or mental health services.

Medical transportation, however, differed widely between the two regions, primarily due to the absence of public transit in Bathurst. A free local bus pass for persons on social assistance or persons with disabilities, senior reduction in public transportation costs and available disabled transit in Cranbrook could reduce the out-of-pocket costs for any of the three caregivers for transportation for treatment, as well as decrease employment disruption to take the care receiver to appointments in British Columbia but not in New Brunswick.

In summary, most reduction in caregiver health-related costs would be indirect through provision of goods and services that caregivers might otherwise have to purchase for the care receiver (e.g., drugs and counselling services). Eligibility criteria for these programs was based on care receiver age, social assistance status, income level, or having a mental condition. Two programs in British Columbia are tailored to persons with mental illness, a drug plan supplying mental health and side effect management drugs and allied health benefits. In New Brunswick persons with low income, social; assistance and seniors are targeted for drug plans and assistance with allied health services and equipment, but there are user fees involved. The care receiver's disability status could make a big difference in the health-related costs. Mary would be likely to have more cost reduction, because of her son's schizophrenia than would Darla and Hal whose care receivers have a mood disorder, because mood disorders do not fit the disability criteria as well as schizophrenia.

Many of the health benefits were tied to the care receiver being on provincial social assistance. The senior care receiver can have more income through even basic OAS + GIS pension than is available through social assistance, but seniors do not have the same health benefits as persons on social assistance (e.g., extended allied health services), so Darla would be likely to pay more for these services than Mary. Hal, however, is likely to be affected by higher costs than the other two because of the practice of combining the income of the spouse caregiver and the care receiver for benefits calculation.

Regional differences exist in the extent of out-of-pocket costs for caregivers because of differing availability of programs, benefits and eligibility criteria. The absence of a universal drug plan and of public transportation for attending treatment activities would make these costs higher for caregivers in New Brunswick than in British Columbia. A major difference between the two provinces is the use of the Extramural program in New Brunswick to replace some hospitalization for acute illness. This program could actually increase caregivers' costs.

Table 13: Program Eligibility Requirements

	Caregiver						Dyad		Care Receiver									
	Labour Status	Spouse in Home	Caregiver Availability	Income	Assets	Family Composition	Co-residence	Relationship	Health Status	Disability Status	On Social Assistance?	Income	Assets	Age	Marital Status	Family Size	Residency	Employment History
Family Responsibility Leave	X							X										
Employment Insurance									X	X								X
Social Assistance	X			X	X	X			X	X		X	X	X		X		X
Disability Assistance										X		X						
Disability Employment Programs									X	X				X				X
Old Age Assistance												X		X	X			
Canada Pension Plan														X	X			X
Canada Pension Plan –Disability									X	X								X
Guaranteed Income Supplement												X		X	X			
Spouse's Allowance								*				X		X	X			
Provincial Income Supplement Programs												X		X	X		X	
Disability Tax Deduction									X	X								
Caregiver Tax Credit							X	X	X			X		X				
Eligible Dependent Credit		X					X	X				X		X				
Tax Credit for Infirm Dependents > 18							X	X	X	X		X		X				
Disability Tax Credit								X	X	X		X			X			
Medical Expenses Tax Credit								X				X						
Provincial tax credits												X		X	X			
Physician/hospital Services									X			X			X		X	
Allied Health								*	X	X	X	X		X	X		X	
Drug Plans								*	X	X	X	X		X	X		X	
Home Care Programs			X					*	X	X	X	X		X	X		X	
Mental Health Programs								*	X	X	X	X	X		X		X	

*Only impacted by spousal relationship

CHAPTER 5: DISCUSSION

The purpose of this study was to identify the kinds of economic costs that are experienced by family and friend caregivers of persons with mental illness and to evaluate how current public policy in Canada affects these costs. Discussion of the study begins with a summary of the findings and brief statements about some implications for policy practice and research. Two major recommendations for policy improvement in light of the study findings are included. This is followed by an analysis of how these findings fit within and enhance current knowledge of the costs of caring, where major knowledge gaps exist that raise questions to inform future research on this population of caregivers and limitations of the study. As one contribution to knowledge development, this section introduces a proposed taxonomy of costs of caring for adults with mental illness.

The findings from this study contribute to the knowledge of impacts of gender, relationship and program policy on costs for caregivers of persons with mental illness. The key findings are that:

- persons in many relationships give care and incur high costs,
- women are more likely to become caregivers; however, gender alone does not predict high caregiving costs once persons are caregivers,
- costs are concentrated among some relationships,
- three relationships may be particularly at risk for high costs, and
- many of the programs that could reduce the costs of caregiving do not serve this population well.

As seen in Table 1, the high costs of caregiving are experienced by persons in many different relationships, including persons in distant relationships and unrelated persons. A greater proportion of persons who are close family members are caregivers and experience high costs. However, the distribution of individual categories of high costs for specific relationships is not statistically different from the distribution of these costs among the total sample, with the exception of daughters, who incur significantly higher unpaid labour costs. These findings indicate that if a person is a caregiver to someone with a mental illness they may well have at least one high cost.

Such variety in caregiver relationships brings into question program eligibility criteria that limit benefits to those in particular (usually close family) relationships. Implications for practice among mental health workers may include changing *family* conferences to make them more inclusive of distantly related or unrelated persons if they are the caregivers. Furthermore, there are implications for social workers who may need to be in touch with caregivers other than family in order to assist them in arranging care and obtaining assistance, if possible, to reduce high care costs.

Variation in kinds of high costs experienced by caregivers in different relationships also raises several questions that have research implications. It is not known whether these adults are receiving all of their care from the "primary caregiver" who was surveyed, whether there is a network of persons contributing to care, or even whether the concept of a "primary caregiver" is a construction that may not fit many persons with mental illness as different times and conditions may make care from certain persons more practical or likely than from other persons. Recent work on caregiving networks for older adults (Keating, Otfinowski, Wenger, Fast, & Derksen, 2003) shows that caregivers are not necessarily interchangeable—the kinds of care people give varies according to their relationship. Much further research is needed to explore these questions about care networks for persons with mental illness.

Results showed that gender alone is not predictive of differences in frequency of incurring high costs once a person is a caregiver, but that gender predicts a higher likelihood for women to become caregiver for someone with a mental illness. This is not the whole story, however, because we know that women are also more likely to become caregivers repeatedly during their lives and to care for more than one person at a time than men, indicating a greater lifetime risk of high costs. There were no longitudinal data available to explore gender differences in cost over time. Furthermore, available data did not allow exploration of other factors such as differences between men and women in educational attainment, wage levels, and employment history that might result in gender differences in cost. Further research is necessary to determine whether statistical lack of differences of cost by gender reflect a relatively uniform but elevated level of costs for both women and men caring for an adult with mental illness, or whether the data were just not sufficiently robust enough to control for factors such as co-residence that might have highlighted such differences.

If, however, there is not a significant difference in costs between men and women while they are caregivers, men caregivers should not be overlooked when planning programs to reduce costs. Men have been largely overlooked in research, because much has concentrated on women. There are practice implications to some of the gender differences noted in the literature review because the information that men caregivers want may differ from what women want. We know that men handle caregiving differently than women with more delegation and more use of formal services, but there is much we do not know about men caregivers. Improving the lot of caregivers in general might go a long way toward dealing with gender inequities in lifetime costs. Several other countries have at least partial economic and pension benefits protection for caregivers (Keefe & Fancey, 1999; White & Keefe, 2005, June). Perhaps this should be considered for Canada as it might increase the number of persons available to give care and might decrease the number of caregivers who need public assistance because of the cumulative costs of care over a lifetime.

A large proportion of the high costs of caregiving are borne by those in close family relationships, particularly parents, spouses, children and sisters. This finding has policy implications, in that incurring multiple high costs could make caring economically very difficult for caregivers and could result in a need for societal assistance, especially in older age if they have given care for many years. Perhaps a policy of early intervention to address caregiver costs might prevent the need for much more societal assistance later, especially if the early intervention promotes the caregivers' ability to remain employed and self-supporting (e.g., increased adult day care availability with transportation provided).

There are several practice implications related to the finding of concentration of costs among certain caregivers. The first is that the roles and obligations of certain relationships may conflict with practice obligations to ensure freedom of decisions and confidentiality for adults who have mental illness. Milliken (2001) described "disenfranchised mothers" who are expected to provide care in the community when their adult child leaves an institution yet receive little or no information about that care while their child is hospitalized due to confidentiality concerns. Beginning discharge planning early in treatment could avoid some of these conundrums. For example, it could allow time for obtaining consent from both the adult with mental illness and the caregiver(s) to have preparation conferences. Offering generic periodic caregiver information sessions, as well, could go a long way toward better preparation for family/friend care while maintaining individual confidentiality and avoiding stigmatization.

Some caregivers groups were likely to experience more than one cost concurrently. Those who experienced high work disruption also were quite likely to have high unpaid labour. This is not a surprising finding because care tasks can interfere with employment due to the unpredictability and episodic nature of a need for care with many mental illnesses. Among mother caregivers who experienced significant work disruption, one third also had 'significant' financial difficulty, once again not a surprising finding if work is being disrupted for care. These findings are important for policy because addressing one cost may actually help with other costs as well. A practice implication for mental health care workers related to this finding is that balancing the needs of care and employment may be difficult and flexibility is likely to be necessary when planning treatment and rehabilitation activities so that they do not interfere with the caregivers' work schedules, because transportation to and from such activities was a frequent caregiver action.

The 'high cost' caregiver profiles created for the program impact analysis were supported by evidence that mother, daughter, and husband caregivers are especially likely to have multiple high costs. However, there was little data to provide precision or detail for developing the profiles. Further research could help to fill in the details that could inform policy development especially in the labour and income security domains so that programs fit especially high cost caregivers better.

Impact analysis of public programs in two regions of Canada revealed that, although most of the programs that were examined had potential to reduce caregiver costs either directly or indirectly, little actual benefit would be realized by these example 'high cost' caregivers, because available programs do not correspond well to the characteristics and needs of the caregivers or the care receivers. Conflicting caregiving and employment demands, income security issues, and their age and relationship were the main areas in which fit with programs was poor for the 'high cost' caregiver profiles.

Some programs do not fit 'high cost' caregiver profiles well because they do not acknowledge the amount of time away from employment and the frequent lack of choice of when that time will be needed for this type of care. Family responsibility leave, while offering some protection for future employment income and benefits for the example 'high cost' daughter caregiver, would be unlikely to provide adequate time in either province for the high unpaid labour that is involved with both regular and crisis caregiving activities. Family responsibility leave does not apply to either the mother or husband 'high cost' caregiver profile used in this study because they are not employed. The long duration of caregiving that was found to be likely for these caregivers would compound employment-related and unpaid labour costs.

No programs were found that provide even partial income assistance for caregiving if employment is reduced or stopped in order to accommodate the need for care. Any potential social assistance from either province was found to be very low, temporary, and to have high economic repercussions related to liquidating and using assets before assistance could be received. The ages of the profiled 'high cost' caregivers' also prevent them from receiving any public pensions, so it was not surprising that 'significant' financial difficulty was frequent among the young retired mother and husband caregivers.

Some programs do not fit the 'high cost' caregiver profiles well because relationship is an issue that affects not only their eligibility, but, for some, also the costs they have to pay in user fees. The 'high cost' caregivers met relationship eligibility for several tax programs and for family responsibility leave. This would not be the case for some more distant relatives and unrelated caregivers who have also been found to incur high costs. However, the profiled mother and the husband 'high cost' caregivers were found to be impacted negatively by some relationship-based program policy.

Income of mother caregivers is combined with that of their husbands to determine housing benefits for disabled adult children living with parents in New Brunswick. This is not the case when a disabled adult lives with caregivers other than parents, a practice that raises the costs of parents more of parents than other caregivers. Income of the husband caregiver and his wife are combined for determining the eligibility and user fees for many goods and services among the health programs. Likewise both incomes are considered for determining the disability income assistance that the wife care receiver is given. This practice of calculating based on both incomes for spouses can greatly increase the costs of spousal caregivers over other caregivers. The eligibility and user fees for these same benefits are only determined by the income of the person with mental illness for those who are single. If the spouse makes too much income, the care receiver may not be eligible for benefits that they could receive if they were single. This is especially costly for spouses of those who are eligible for disability assistance because the care receiver's disability income amount is decreased by the amount of their spouse's income (with very little exemption). When benefits are tied to receiving disability assistance, calculating based on combined income may also trap the caregiving spouse in poverty in order to keep the disability assistance active so that they can afford costly treatment and support services, or it may increase the caregiving spouse's unpaid labour costs to perform the services that would otherwise be available if the caregiver were single.

Disability definitions were a major area in which fit with programs was poor for the 'high cost' care receiver profiles. Some programs do not correspond well to the kind and course of this type of illness. Programs are often better suited to acute rather than chronic, physical rather than mental, and permanent rather than episodic disorders or disabilities. Eligibility criteria were found to vary widely. "Severe" and "prolonged" duration is necessary for CPP-D, over 2 years or with frequent recurrence for long periods for British Columbia disability assistance, indefinite duration with "no substantial improvement" for New Brunswick disability assistance, and at least one continuous year of severe interference with activities of daily living for the federal Disability Tax Credit.

Being able to work matters for receiving either the disability supports benefits or the supplementary medical expenses tax credit intended for working disabled people which can reduce caregiver costs indirectly. However, not being able to work does not necessarily qualify a person to receive some disability benefits such as the Disability Tax Credit. But being able to work enough to earn $844.59 per month, disqualifies applicants from being able to receive CPP-D. Yet this amount of income would not be enough to live on, would be too much to qualify for social assistance in either province, and would be likely to require much caregiver economic support.

The potential for reduction of caregiver costs varied according to whether the care receiver was considered disabled, because of the practice of tying benefits and income to disability status. Based on the current criteria in the regions examined, many people with mood disorders are unlikely to qualify as disabled for several programs because of the episodic course of their illness and because most are able to perform activities of daily living and yet are unlikely to be able to maintain employment when ill. This could negatively impact the caregiving costs of both the daughter and husband 'high cost' caregiver profiles.

In all, the poor fit of programs that could reduce caregiver costs is consistent with the conclusion of Prince (2004) that the "patchwork" of Canadian disability policy needs much improvement.

Recommendations for Policy Development

Many present programs have potential to reduce the costs of caregivers considerably, but are unlikely to be effective because they do not apply well to those who are incurring high costs caring for someone with mental illness, or to the persons who have a mental illness. This study raises questions about two policy strategies that may be especially relevant to the costs of giving care to a family member or friend with mental illness. These are the use of relationship and disability status as criteria for benefit eligibility.

Findings from the present study show the potential for much negative economic impact when relationship is used as a criterion for determining eligibility for and amounts of benefits. It may be argued that limiting benefits to persons in the closest relationships targets those who give care most often, and this is seen to some degree in the programs that were examined. Yet the findings show that many caregivers incurring high costs are distant kin or non kin who do not benefit at all.

Some are closely-related caregivers such as parents and spouses are more likely to have multiple high costs. Yet several programs that could reduce caregiver costs preclude or truncate their eligibility, leading to significant differences in their costs, and requiring more of caregivers who already are more likely than others to experience multiple high costs.

Lack of correspondence of programs with characteristics of mental illness can increase costs significantly. Conflicting disability definitions can result in being considered disabled for one program but not for another. Some kinds of mental illness, especially those with an episodic course, are less likely to meet eligibility requirements to be considered disabled and yet the persons may not be able to maintain enough employment to support themselves. Many benefits are dependent on being designated as disabled and then remaining disabled. Although there are some exemptions for work income, if a person on disability works too much they may risk losing benefits that they may not be able to work enough to afford. As Provencher, Gregg, Crawford, & Mueser (2002) emphasize, work has an important role in recovery from mental illness, but recovering persons may be held back by the fear of losing benefits by working too much.

Supplementing the costs of someone who cannot work enough to support themselves can seriously impact on the caregiver's costs. Some family caregivers describe being trapped in a situation that can require caregiver subsidization of care receiver expenses throughout life because the care receiver lives on a very low disability income in order to afford treatment (see Government of Canada, 2006, for testimony from caregivers about this condition). These two eligibility criteria, relationship and disability status, intersect especially for spouses because the spouse's income is also considered in determining whether the care receiver qualifies for disability support and services in both provinces. This has significant implications for the employment of the spouse. If they work too much, they may lose the benefits that are most needed for their spouse. They can be trapped in poverty throughout life because they give care. This is counterproductive for strengthening the spousal relationships that provide so much caregiving at much personal expense for this group of people.

Existing programs in which benefits that are necessary for persons with mental illness are tied to either disability status or to receiving social assistance is counterproductive to recovery especially with illnesses that are episodic. Hollander and Prince (2002) argue that a different philosophy of care provision is needed for persons with mental illness as opposed to more curable illnesses, a philosophy that is based on "enablement" to function at their highest level possible with the capacity to have more help from health and/or social services when needed.

Based on the results of this study, two major recommendations are offered.

1. Relationship should be removed from the eligibility requirements for programs that can reduce caregiver costs including Caregiver Tax Credit, Eligible Dependent Tax Credit, Infirm Dependents >18 Years Tax Credit, Medical Expenses Tax Credit, Social Assistance and Disability Programs in both provinces, and from health programs that determine benefits based on combined income.
2. *A major examination and overhaul of disability definitions for consistency and for congruence with impairment related to mental illness is needed.* This would need to involve Canada Pension Plan – Disability, Disability Tax Credit, Medical Expenses Credit, social assistance and disability employment programs for both provinces, health-related benefit programs for both provinces and the subsidized transit pass program in British Columbia. A major step toward enabling persons with mental illness to function as active members of society

(and for reducing the costs of caregivers) would involve programs that uncouple qualification for benefits from illness or social assistance status and instead base them on income of the person who would receive the benefit. This would be a long-term goal. It would require improved ease of entry and exit from disability/social assistance programs when the person changes significantly. Benefits that require registration with a Mental Health Centre might be an answer, although this could be considered stigmatizing.

How These Findings Fit Within and Enhance Our Knowledge of Caregiver Costs

The findings of this study provide further evidence to support current caregiving research that shows that there are significant economic impacts for those who give care for family members and friends. Findings that high costs are widespread among many relationships, while being particularly heavy for some, emphasizes the relevance of further study on this population of caregivers who provide a vital societal service (Waring 2003) yet pay high costs to do so.

Twice as many women as men provide care. Yet acknowledgement of gender differences in likelihood to care has not been translated to policy that is friendly to women or men who are worker/caregivers. The Adult Worker Model (Lewis, & Giullari, 2005) seems very evident in the social assistance programs that were examined in both regions. Everyone is expected to be working and caring (in most cases) does not qualify as working for the purposes of social assistance. Meanwhile, health reforms increase pressure on families to give care (Gerstel, & Gallagher, 2001). This is especially true for persons with mental illness because community options for formal care have not kept pace with decreases in institutional options, so family and friends have little other options than to give care.

The focus of research on care for persons with mental illness has seldom been on the economic costs. Yet many studies have been done to document the savings to the health care system by utilizing the informal rather than formal care system. Even research that focuses on supporting caregivers of persons with mental illness has contained little on economic aspects of care, especially as it is impacted by public programs. Recently researchers have begun to look at the costs of caregiving for persons with cancer and HIV. Current search of the literature still finds very little on financial costs to family and friend caregivers of persons with mental illness.

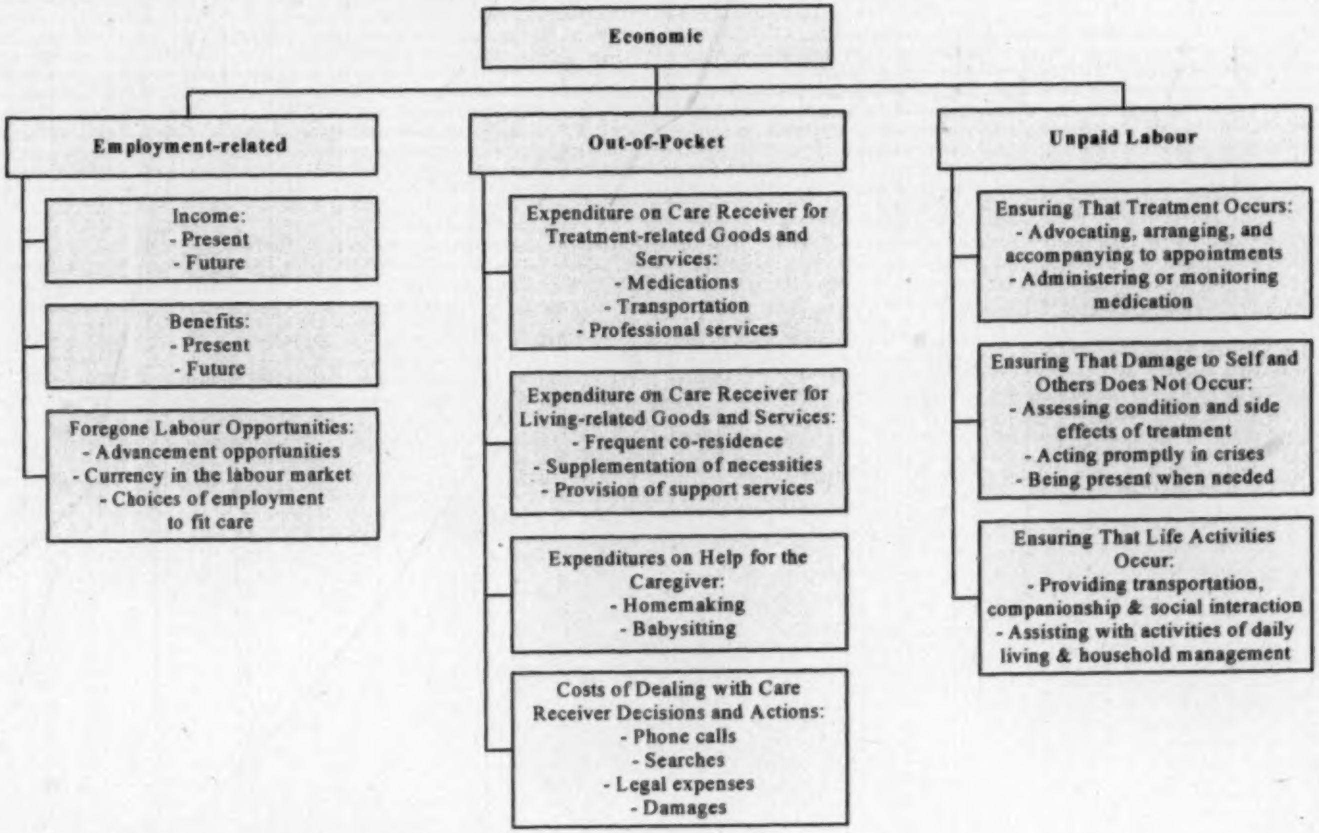
The current study has provided a small piece of a puzzle that impacts all of us in one way or another. Much more research remains to be done. Health Canada's survey has contributed previously unknown information toward the knowledge of costs of caregivers for a person with mental illness in Canada. It is hoped that contribution to this knowledge base will continue with future national surveys that may provide more quantitative as well as qualitative data on the details of the characteristics of caregivers, care receivers, and dyadic characteristics and of their costs. If sample size of future surveys is adequate for multifactorial analysis of information on these caregivers, identification of characteristics that are associated with caregiver costs or that moderate impact of programs could have significant implications for policy development.

Further Contribution toward a Taxonomy of Caregiver Costs

Much of our current knowledge concerning caregiver costs is based on research on care to older adults. Policy changes being made in Canada often cite information from this knowledge base. We do have an aging population, but we dare not overlook other caregivers who may have different costs that are amenable to public program intervention. The findings of the current study expand our knowledge of caregiving costs by comparing what is known about the costs of caring for older adults with the costs of caring for adults with mental illness and identifying some gaps indicating a need for future research Such research could inform policy to better address the costs of caregivers who have some different costs and a much longer period of incurring them.

Much difference is seen in the costs that are involved with these two kinds of care. This current study began with a taxonomy of hidden costs of care to older adults (Fast, et al, 1999) to guide the literature search because no taxonomy was found for costs of caregivers for adults with mental illness. All of the same major categories of caregiving costs were represented in the mental illness literature that are found in the literature on costs for giving care to older adults: employment-related costs, out-of-pocket costs and unpaid labour. But the subcategories of costs differ because of characteristics of the disorders, treatments, and needs for care. A contribution of this study to current knowledge is a taxonomy that reflects the costs for caregivers for an adult with mental illness (see Figure 1).

Figure 1: Taxonomy of the Costs of Care for Adults with Mental Illness


Economic
Employment-related
Income:
- Present
- Future
Benefits:
- Present
- Future
Foregone Labour Opportunities:
- Advancement opportunities
- Currency in the labour market
- Choices of employment to fit care
Out-of-Pocket
Expenditure on Care Receiver for Treatment-related Goods and Services:
- Medications
- Transportation
- Professional services
Expenditure on Care Receiver for Living-related Goods and Services:
- Frequent co-residence
- Supplementation of necessities
- Provision of support services
Expenditures on Help for the Caregiver:
- Homemaking
- Babysitting
Costs of Dealing with Care Receiver Decisions and Actions:
- Phone calls
- Searches
- Legal expenses
- Damages
Unpaid Labour
Ensuring That Treatment Occurs:
- Advocating, arranging, and accompanying to appointments
- Administering or monitoring medication
Ensuring That Damage to Self and Others Does Not Occur:
- Assessing condition and side effects of treatment
- Acting promptly in crises
- Being present when needed
Ensuring That Life Activities Occur:
- Providing transportation, companionship & social interaction
- Assisting with activities of daily living & household management

Adapted from Fast et al., 1999 with permission

Employment-related Costs

The highest economic costs for caregivers for both older adults and for adults with mental illness would be likely to result from employment-related costs since employment disruption related to caregiving was found to be a frequent cost in both instances. However, we do not yet have quantitative data for those caring for persons with mental illness in order to compare employment hours and to compare unpaid labour hours for the two groups. This is one area in which pressing questions remain to be answered in future research, because there were no Canadian time-use data found for hours spent in caregiving for persons with mental illness. We do know from a US pilot study, that, as of 1999, it was estimated that well over one million dollars CDN can be lost in wages and pension benefits through caring 8 hours per week for 5-7 years for an older adult (Mature Market Institute, 1999). We also have documentation in the mental health literature of over 32 hours per week being spent in contact for many European caregivers of persons with schizophrenia (Meijer et al., 2004) and of 30% of Canadian caregivers for persons with mental illness caring for 11 years or more (Health Canada, 2004).

These findings point to potentially serious implications for employment-related losses especially for 'high cost' daughter caregivers for an adult with mental illness who would experience present and future loss of income and benefits if she misses work and foregone labour opportunity costs related to adjusting her employment to fit the care (Wuest, 2000). Adjusting her employment might prevent advancement or involve working at a less desirable job in order to fit the schedule required for this kind of care with employment (Chaffey & Fossey, 2004). However, the mother and husband 'high cost' caregivers may suffer even greater employment-related losses because they retired so early and have costs related to foregone labour opportunities (Szinovacz & Davey, 2005), such as lost benefits and having less income to receive than they would have had if they contributed longer to pension plans or had longer to save for retirement (Evandrou & Glaser, 2003). Although we know much about how caregivers for older adults adjust their employment (such as using vacation and sick time for care) (Fast et al., 2000), there is a gap in knowledge about what is occurring among caregivers for adults with mental illness. We need to know how caregiving is impacting employment in order to begin to look at ways that programs may reduce the related costs and this is another area for future research.

Unpaid Labour

The details of unpaid labour costs are not specified in the taxonomy of hidden costs for older adults, but Cranswick (2003) breaks down the unpaid labour for older adults according to "inside the house, outside the house, transportation and personal care" (p. 12). Fast et al. (1999) describe unpaid caregiving work as "similar to that of unpaid household work" (p. 304), and as something which is seen as "costless." In the mental illness literature, one can find description of unpaid labour that may include housework yet may require a high level of knowledge about management of the illness (Doornbos, 2001). Such high level care borders on (and sometimes somewhat overlaps) that which is provided by professional caregivers (Clark, Xie, Adachi-Meija, & Sengupta, 2001).

A particular quality of the unpaid labour that is described for these caregivers is a constant vigilance that may continue throughout life and which can have significant implications related the amount of time caregivers of adults with mental illness may be spending in unpaid labour and how this may be impacting their employment. Although some vigilance may be a part of care to older adults, it is generally not a constant activity except in times of severe illness, dementia or palliative care. This study found that for those instances, there are programs available that offer respite, but that respite was not as readily available to caregivers of adults with mental illness.

A synthesis of what the mental health literature says about caregiving tasks can be summarized as ensuring that treatment occurs, ensuring that damage to self and others because of the care receiver's illness does not occur and ensuring that life activities occur. The latter subcategory subsumes much of what is described as unpaid labour for older adults whether it occurs inside or outside of the house: providing transportation, companionship, and social interaction as well as assisting with activities of daily living and household management. The former two categories are likely to be additional to the unpaid labour required for older adults and may provide especially high hidden costs, because they do not fit our present caregiving categories well. Some activities that are a part of ensuring that treatment occurs include advocating, arranging, and accompanying to appointments and administering or monitoring medications. Some activities that are a part of ensuring that damage to self and others does not occur include assessing condition and side effects of treatment, acting promptly in crises, and being present when needed.

Out-of-pocket Costs

The taxonomy of costs for care of older adults lists expenditures on the care receiver and on help as two cost subcategories. Both of these occur for caregivers of adults with mental illness also. However, an important distinction is that treatment may go on throughout life and providing additional support for the life of the care receiver, when needed, aside from their treatment, may also continue throughout life. Some of the conditions that necessitate this involve both goods and services. For this reason, goods and services are divided into two subcategories that illustrate this differentiation.

The program impact analysis showed that, depending on the availability of programs in the region, those who care for an adult with a mental illness may pay high costs for goods and services, such as medication and psychologist fees, that are often considered essential to treatment of the care receiver and yet are not necessarily supplied as a benefit of medical plans available to all Canadians. Out-of-pocket costs for transportation might seem to be a debatable expense that does not belong under treatment costs, because many people need transportation for medical appointments. However, the symptoms of some of the illnesses and the effects of some medications may preclude driving throughout life for some persons with mental illness (Lehne, 2007; Townsend, 2006). The costs for providing transportation for persons with mental illness may be higher than for older adults due to the frequency that it is needed because, as the program impact analysis for these regions showed, checkups, counseling, rehabilitation, and socialization events typically occur at mental health treatment centres.

Some versions of the taxonomy of care to older adults include money transfers, a category that is likely to be different. This raises a question about many contributions that may occur in both directions and this needs further research in order to be able to comment on it with an adequate evidence base. Some older adults have been noted in the literature to contribute economically to their care from the results of a lifetime of employment (Koh, & MacDonald, 2006) and older adults are generally eligible for some pension support, which at minimum levels was still found to be likely to exceed disability assistance or social assistance (for those who were not deemed to be disabled). However, for persons with mental illness there is evidence in the literature of low employment prospects (Baron & Salzer, 2002; Canadian Mental Health Association, 2001) and of frequent poverty (Wilton, 2004), resulting in supplementation by the caregiver of necessities, if the care receiver cannot afford them (Milliken, 2001). Transfers of money from the caregiver would likely be deducted from any disability or social assistance, based on the information found in this study.

Out-of-pocket expenditures on the care receiver also may differ due to senior benefits. Reduced fees for seniors were found to exist for many goods and services such as co-payments for medications and professional services. These lower fees would not be available to caregivers of younger adults with mental illness. As well, caregivers of older adults seldom live with the senior (Cranswick, 2003), but the literature tells us that persons with mental illness often do live with their caregiver (Botsford & Rule, 2004). There are indications that this may be true for the 'high costs' caregivers, although this is somewhat uncertain, since the available data only supplied information about whether care occurred in the caregiver's home. Co-residence could be a source of caregiver cost for both goods and services. However, transportation for the caregiver and costs of supportive services like homemaking, which was one of the most frequent costs listed by caregivers (Health Canada, 2004), are noted for those who live at a distance. Whether the recorded homemaking was purchased for the caregiver in order to free up time to give care, or to provide supportive services so the care receiver could maintain separate accommodations, was not clear in the Health Canada survey (2004), but either could be a source of higher caregiver costs. The occurrence of co-residence with caregivers in Canada also should be explored further in the future as finding safe adequate housing has been identified as especially problematic for persons with mental illness (Government of Canada, 2006). The current study found that housing allowances for disabled persons and persons on social assistance are very small in either region, so co-residence is likely because a safe, separate residence may not be affordable.

One cost area noted in the literature that is perhaps unique to the care of adults with mental illness involves paying costs of dealing with the results of the actions of the person who has mental illness. This is tentatively offered as a potential caregiving cost although it may not be amenable to any public intervention This may include such items as bail, legal services fees, or damage deposits that are forfeited (Milliken & Northcott, 2003). This may have particularly serious implications for the costs of spouses who give care and who may have shared responsibility for expenses incurred by their spouse. This is also an area in which we have a knowledge gap.

In conclusion, caregiving for family members and friends who have mental illness has many costs, some that are unique to the persons involved, the illness, the treatments, the disability and the stigma surrounding this group of illnesses. This examination of who cares, what it costs them, and how policy addresses their costs is acknowledged as a beginning exploration with many questions left unanswered. This study has shown that relationship and gender may influence caregiving costs in the contexts of who becomes a caregiver, what their caregiving role demands, and how policy addresses their costs. The impact analysis for two regions has shown that regional differences in policy and programs exist that can result in significant differences in costs for caregivers because of where they live. Much future research is needed to contribute to a better fit of programs to address the costs of caregivers for adults with mental illness.

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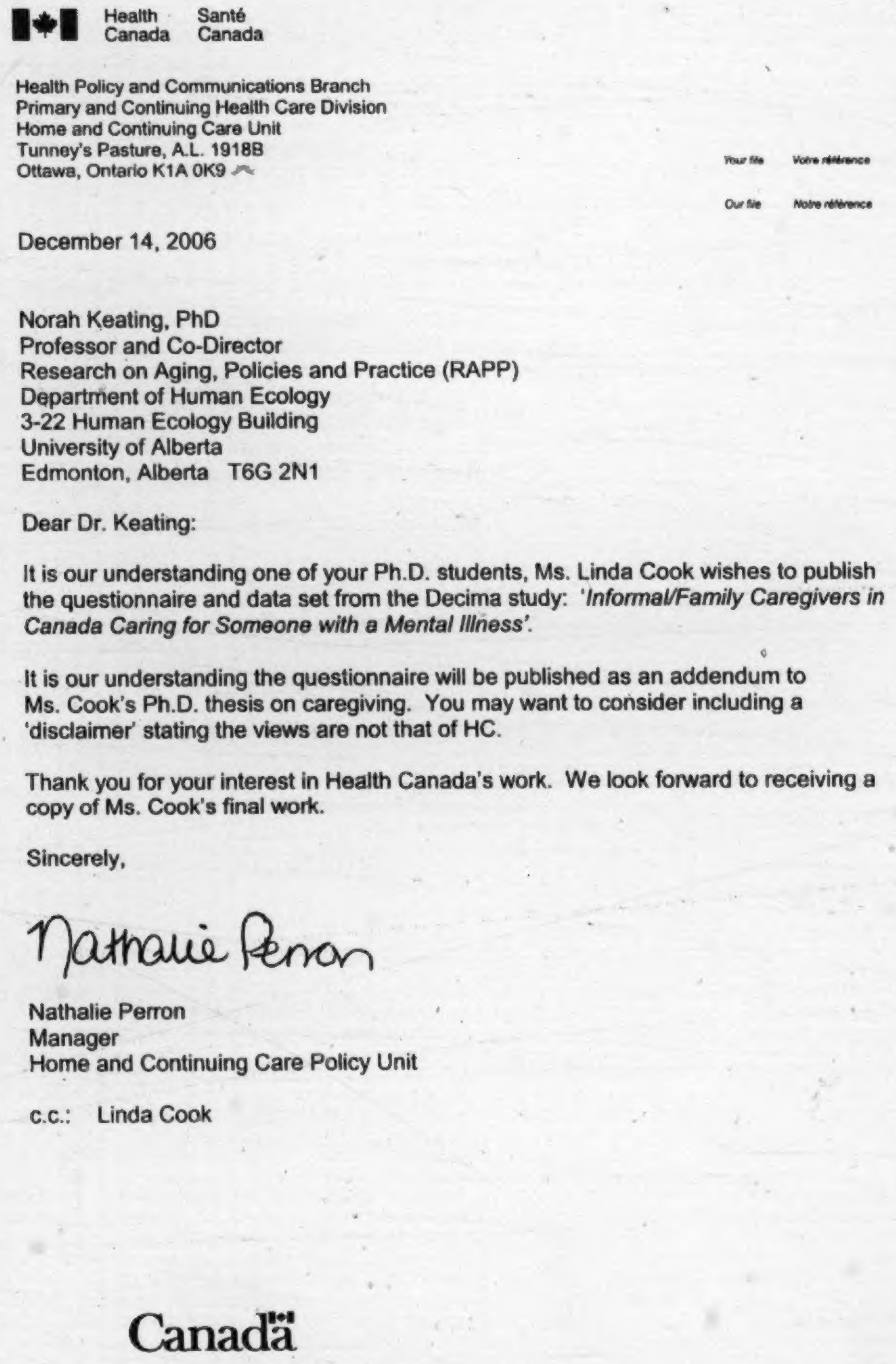
APPENDIX A: SURVEY



Health Canada
Santé Canada

Health Policy and Communications Branch
Primary and Continuing Health Care Division
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Tunney's Pasture, A.L. 1918B
Ottawa, Ontario K1A 0K9

Your file Votre référence

Our file Notre référence

December 14, 2006

Norah Keating, PhD
Professor and Co-Director
Research on Aging, Policies and Practice (RAPP)
Department of Human Ecology
3-22 Human Ecology Building
University of Alberta
Edmonton, Alberta T6G 2N1

Dear Dr. Keating:

It is our understanding one of your Ph.D. students, Ms. Linda Cook wishes to publish the questionnaire and data set from the Decima study: '*Informal/Family Caregivers in Canada Caring for Someone with a Mental Illness*'.

It is our understanding the questionnaire will be published as an addendum to Ms. Cook's Ph.D. thesis on caregiving. You may want to consider including a 'disclaimer' stating the views are not that of HC.

Thank you for your interest in Health Canada's work. We look forward to receiving a copy of Ms. Cook's final work.

Sincerely,

Nathalie Perron

Nathalie Perron
Manager
Home and Continuing Care Policy Unit

c.c.: Linda Cook

Canada

APPENDIX A: SURVEY

Health Canada

Informal/Family Caregivers in Canada Caring for Someone with a Mental Illness - 2004

Final Questionnaire

Introduction

Good morning/afternoon/evening. My name is ______________ and I am calling on behalf of Health Canada from Decima Research. We are conducting a survey to help Health Canada better understand the needs of people who provide care to someone who has a mental illness, such as depression, schizophrenia, or other illnesses.

[IF ASKED: Decima is a professional research company hired by Health Canada to conduct this survey]
[IF ASKED: The survey will take about 15 minutes to complete]
[IF ASKED: The survey is registered with Canadian Association of Marketing Research Organizations]

A. Screening for Eligibility

[NOTE TO INTERVIEWER: IF AT ANY POINT DURING THE SCREENER, THE PERSON YOU ARE TALKING TO SAYS THAT HE/SHE IS THE ONE RECEIVING CARE, SKIP TO Q5C]

1a. Do you or someone else in your household currently provide unpaid care for a family member, friend or neighbour with a mental illness?

[Note to Interviewer: relevant diseases would include: Mood disorder (major depression, bipolar disorder/manic depression and dysthymia, post-partum depression); Schizophrenia; Anxiety disorder (generalized anxiety disorder, specific phobia, post traumatic stress disorder, social phobia, obsessive-compulsive disorder, panic disorder), Personality disorder; Eating disorder (anorexia, bulimia, binge eating disorder). However it does not include dementia type disorders such as Alzheimer disease, or addictions, developmental delays and acquired brain injuries.]

- Yes, myself	SKIP TO Q.2a
- Yes, another person in the household	SKIP TO Q.2a
- No	
- Don't know/No answer	

1b. (IF NO/DON'T KNOW TO Q.1a). Have you or someone in your household provided unpaid care to someone with a mental illness in the past 12 months?

- Yes, myself	SKIP TO Q.2b
- Yes, another person in household	SKIP TO Q.2b
- No	THANK AND ASK FOR REFERRAL
- Don't know/No answer	THANK AND ASK FOR REFERRAL

2a. (IF YES TO Q.1a) Do [you/this other person] provide unpaid care in your home, in the recipient's home, or somewhere else, such as in a hospital or a supervised residential facility?

- In the home	SKIP TO Q.4a
- In their own home	SKIP TO Q.4a
- Somewhere else	SKIP TO Q.3
- Don't know/No answer	SKIP TO Q.3

2b. (IF YES TO Q.1b) Did [you/this other person] provide unpaid care in your home, in the recipient's home, or somewhere else, such as in a hospital or a supervised residential facility?

- In the home	SKIP TO Q.4b
- In their own home	SKIP TO Q.4b
- Somewhere else	
- Don't know/No answer	

3. (IF SOMEWHERE ELSE/DON'T KNOW) In what type of setting or facility [is/was] the person needing care situated?
READ CATEGORIES IF NECESSARY - CODE MORE THAN ONE IF MENTIONED

- Nursing home or long-term care facility	THANK AND ASK FOR REFERRAL
- Hospital	THANK AND ASK FOR REFERRAL
- Hospice	THANK AND ASK FOR REFERRAL
- Supervised boarding home	THANK AND ASK FOR REFERRAL
- Supportive housing	THANK AND ASK FOR REFERRAL
- Shelter for the homeless	THANK AND ASK FOR REFERRAL
- Correctional institution	THANK AND ASK FOR REFERRAL
- Residential addictions treatment centre	THANK AND ASK FOR REFERRAL
- Residential mental health treatment centre	THANK AND ASK FOR REFERRAL
- Other (SPECIFY ______________)	
- (IF NOT AN INSTITUTION AND 1A GO TO 4A	
- IF NOT AN INSTITUTION AND 1B GO TO 4B)	
- Don't know/No answer	THANK AND ASK FOR REFERRAL

4a. Are [you/this other person] the main unpaid caregiver to the person needing care, or does someone else possibly a professional or an institution provide most of the care needed?
[IF ASKED: Being the main caregiver means providing day-to-day care, whether or not professional support is also being provided]

- Am main caregiver	SKIP TO SECTION B
- Someone else in our household is main caregiver	SKIP TO Q.5a
- Someone else, not living in the household is main caregiver	THANK AND ASK FOR REFERRAL
Someone else such as professional or an institutions is main caregiver	THANK AND ASK FOR REFERRAL
- Depends/Don't know	THANK AND ASK FOR REFERRAL

4b. Were [you/this other person] the main unpaid caregiver to the person needing care, or did someone else possibly a professional or an institution provided most of the care needed?
[IF ASKED: Being the main caregiver means providing day-to-day care, whether or not professional support is also being provided]

- Am main caregiver	SKIP TO SECTION B
- Someone else in our household is main caregiver	SKIP TO Q.5a
- Someone else, not living in the household is main caregiver	THANK AND ASK FOR REFERRAL
Someone else such as professional or an institutions is main caregiver	THANK AND ASK FOR REFERRAL
- Depends/Don't know	THANK AND ASK FOR REFERRAL

5a. (IF CAREGIVER IS SOMEONE OTHER THAN THE RESPONDENT) May I speak with the person in your household who [is/was] providing this care?

IF NOT AVAILABLE, ARRANGE CALL-BACK (CREATE A DISPOSITION CODE)

IF STARTING WITH NEW RESPONDENT, BEGIN WITH INITIAL INTRODUCTION AND THEN THE FOLLOWING (SECTION B):

[NOTE TO INTERVIEWER: ASK ONLY IF RESPONDENTS SELF-IDENTIFIES AS THE ONE RECEIVING CARE FOR A MENTAL ILLNESS]

5c. Is there someone in your household who helps you by providing day-to-day support.

- Yes (GO TO 5D)
- No THANK AND TERMINATE **DO NOT ASK FOR REFERRAL**

5d. May I please speak with that person?

IF NOT AVAILABLE, ARRANGE CALL-BACK (CREATE A DISPOSITION CODE)

IF STARTING WITH NEW RESPONDENT, BEGIN WITH INITIAL INTRODUCTION AND THE SCREENER

CONTINUE WITH CURRENT OR FORMER CAREGIVER

REFERRAL SCRIPT: Do you know of ANYONE who provides unpaid care for someone with a mental illness in a non-institutional setting such as their home and who might be interested in participating in this study?

IF YES, RECORD NAME AND NUMBER OF REFERRAL **AND** NAME AND NUMBER OF REFERRING INDIVIDUAL.

IF NO, THANK AND TERMINATE

B. Type of Recipient/Reasons for Care

I would now like to ask you about your activities and experiences in providing care to a person with mental illness in either your home or in their home. Please be assured that all of your answers will remain strictly confidential, and will not be associated with your name in any way. Once again, the purpose of this survey is to help Health Canada better understand the needs of people like yourself who are providing this type of care.

6. What [is/was] the care recipient's relationship to you?
DO NOT READ - CODE ONE ONLY
(IF UNCLEAR, PROMPT)
Am I correct in understanding that the person is your [Q.6 response]

- Wife
- Husband
- Spouse/partner (includes common law/same sex partner)
- Grandfather
- Grandmother
- Great-grandfather
- Great-grandmother
- Mother
- Father
- Mother-in-law
- Father-in-law
- Sister
- Brother
- Sister-in-law
- Brother-in-law
- Son
- Daughter
- Son-in-law
- Daughter-in-law
- Step-father
- Step-mother
- Step-son
- Step-daughter
- Aunt
- Uncle
- Cousin
- Niece
- Nephew
- Roommate
- Friend
- Neighbour
- Other (SPECIFY ____________________)
- Refuse/No answer THANK AND TERMINATE

IF GENDER OF THE CARE RECIPIENT IS NOT CLEAR (SPOUSE/PARTNER, COUSIN, FRIEND, NEIGHBOUR, OTHER) GO TO Q6N, OTHERWISE SKIP TO Q8a

6n. What is the gender of your (INSERT Q6)?
- Male
- Female

8a. What is the age of your [Q.6 response]?
READ CATEGORIES IF NECESSARY - CODE ONE ONLY
- Under 18 years of age
- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 to 74
- 75 to 84
- 85 and older
- No Response/Refused

7. [Are/were] there any other people ill or disabled, who you [are/were] caring for?
7a
- Yes
- No (SKIP TO Q9)

7b. What [is/was] that person's relationship to you?
(IF UNCLEAR PROMPT) Am I correct in understanding that the person is your [Q.7b response]

DO NOT READ - CODE MORE THAN ONE IF MENTIONED
- Wife
- Husband
- Spouse/partner (includes common law/same sex partner)
- Grandfather
- Grandmother
- Great-grandfather
- Great-grandmother
- Mother
- Father
- Mother-in-law
- Father-in-law
- Sister
- Brother
- Sister-in-law
- Brother-in-law
- Son
- Daughter
- Son-in-law
- Daughter-in-law
- Step-father
- Step-mother
- Step-son
- Step-daughter
- Aunt
- Uncle
- Cousin
- Niece
- Nephew
- Roommate
- Friend
- Neighbour
- Other (SPECIFY ____________________)
- Refuse/No answer

IF GENDER OF THE CARE RECIPIENT IS NOT CLEAR (SPOUSE/PARTNER, COUSIN, FRIEND, NEIGHBOUR, OTHER) GO TO Q7c, OTHERWISE SKIP TO Q8b

7c. What is the gender of your (INSERT Q7b)?

- Male
- Female

8b. (ASK IF AT LEAST ONE SELECTION IN Q7a)

And what is the age of your [Q.7 response]
READ CATEGORIES IF NECESSARY - (FOR EACH OF THE MENTIONS)

- Under 18 years of age
- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 to 74
- 75 to 84
- 85 and older
- No Response/Refused

9. (IF MORE THAN ONE PERSON CARED FOR, ASK ABOUT THE ONE MENTIONED IN Q.6)
How long have you been caring for your [Q.6 response]?
READ CATEGORIES IF NECESSARY - CODE ONE ONLY

- Less than a month
- 1 to 3 months
- 4 to 6 months
- 7 to 12 months
- 1 to 2 years
- 3 to 5 years
- 6 to 10 years
- More than 10 years
- Don't know/No answer

10. [Is/was] the illness affecting your [Q.6 response] something that [is/was] short term, that [is/was] less than three months, medium term that [is/was] three months to six months, or something that [is/was] longer term?

- Short term/Acute (less than three months)
- Medium term (three to six months)
- Long term (longer than six months)

VOLUNTEERED

- Uncertain/cannot say at this time
- Don't know/No answer

11. What is the diagnosed condition for which your [Q.6 response] [requires/required] care: SELECT FROM LIST ONLY DIAGNOSED CONDITIONS – RECORD "NON-DIAGNOSED" UNDER OTHER.

DO NOT READ - CODE MORE THAN ONE IF MENTIONED

- Mood disorder (major depression, bipolar disorder/manic depression and dysthymia, post-partum depression)
- Schizophrenia
- Anxiety disorder (generalized anxiety disorder, specific phobia, post traumatic stress disorder, social phobia, obsessive-compulsive disorder, panic disorder)
- Personality disorder
- Eating disorder (anorexia, bulimia, binge eating disorder)
- Other (RECORD, IF NONE OF THE DIAGNOSES IS A MENTAL DISORDER BUT DEMENTIA, ADDICTION OR DEVELOPMENTAL DEFECTS, GO TO DEMOGRAPHICS)
- Rather not say (GO TO Q12)
- Don't know (SKIP TO DEMOGRAPHICS)
- Not diagnosed SKIP TO DEMOGRAPHICS

IF Q2B (HAVE CARED IN THE PAST 12 MONTHS), OTHERWISE SKIP TO Q12

11N. You mentioned that you have cared for your [Q.6 response] in the past 12 months, but do not now, why is that?

DO NOT READ

- Recovered
- Can maintain him/herself
- Institutionalized
- Died
- Death by suicide
- Other (RECORD)
- Rather not say
- DK/NA

12. Which of the following are reasons why you [are/were] providing the care to your [Q.6 response]? [Is/was] it because:

READ AND ROTATE - CODE ALL THAT APPLY
READ SLOWLY TO ALLOW ANSWERING YES OR NO

a. You [choose/chose] to be the one providing the care
- Yes
- No

VOLUNTEERED
- Don't know/No answer

b. You [feel/felt] it [is/was] your responsibility
- Yes
- No

VOLUNTEERED
- Don't know/No answer

c. No one else [is/was] available to do it
- Yes
- No

VOLUNTEERED
- Don't know/No answer

d. A lack of available home care services
- Yes
- No

VOLUNTEERED
- Don't know/No answer

e. A lack of available mental health services
- Yes
- No

VOLUNTEERED
- Don't know/No answer

13. Do you feel that you had other reasonable options when you chose to take on responsibility for providing care to your [Q.6 response]?

- Yes
- No
- Don't know/No answer

C. Caregiving Tasks Performed

14. I will now read to you a list of tasks. In each case please tell me whether you [perform/ed] this task for your [Q.6 response] on a daily basis, occasionally, rarely, or never? Starting with:
READ IN SEQUENCE

a. Providing or monitoring medications
b. Providing injections
c. Monitoring symptoms
d. Providing emotional support during a crisis
e. Assistance with personal grooming
f. Advocating for the person to receive help
g. Arranging and coordinating services and appointments
h. Going to appointments with the person
i. Providing companionship
j. Paying bills

- Daily basis
- Occasional basis
- Rarely
- Never

VOLUNTEERED
- Don't know/No answer

15. [Are/were] there any other tasks you [perform/ed] for your [Q.6 response] on at least an occasional basis?
IF "YES" – PROBE: Which tasks did you perform?
CODE ALL THAT APPLY, USE PRE-CODES FROM 14

- Other (SPECIFY)
- No/None
- Don't know/No answer

16. Do you feel you [have/had] the necessary skills and capabilities for properly caring for your [Q.6 response]?

- Yes
- No
- Don't know/No answer

17. With what types of caregiving tasks, if any, do you feel that you [could use/could have used] some help in caring for your [Q.6 response]?

DO NOT READ - CODE ALL THAT APPLY

a. Providing or monitoring medications
b. Providing injections
c. Monitoring symptoms
d. Providing emotional support during a crisis
e. Assistance with personal grooming
f. Advocating for person to receive help
g. Arranging and coordinating services and appointments
h. Going to appointments with the person
i. Providing companionship
j. Paying bills

- Other (SPECIFY ________________________)
- None
- Already getting help
- Don't know/No answer

SHORT TERM CURRENT CAREGIVERS (LESS THAN 12 MONTHS), IFQ9 IS LESS THAN 12 MONTHS

18a. During the past [few (IF Q9 IS 6 MONTHS OR LESS)/several (IF Q9 IS 6 MONTHS TO 12 MONTHS)] months were you paying out-of-pocket costs to provide care to your [Q.6 response]?

- Yes	
- No	SKIP TO Q.21
- Don't know/No answer	SKIP TO Q.21

SHORT TERM PAST CAREGIVERS (LESS THAN 12 MONTHS), IFQ9 IS LESS THAN 12 MONTHS

18b. During the time you were a caregiver did you pay out-of-pocket costs to provide care to your [Q.6 response]?

- Yes	
- No	SKIP TO Q.21
- Don't know/No answer	SKIP TO Q.21

LONG TERM CURRENT CAREGIVERS (MORE THAN 12 MONTHS), IFQ9 IS MORE THAN 12 MONTHS

18c. In the past 12 months, have you paid out-of-pocket costs to provide care to your [Q.6 response]?

- Yes	
- No	SKIP TO Q.21
- Don't know/No answer	SKIP TO Q.21

LONG TERM PAST CAREGIVERS (MORE THAN 12 MONTHS), IFQ9 IS MORE THAN 12 MONTHS

18d. During the last year you were a caregiver, did you pay out-of-pocket costs to provide the care to your [Q.6 response]?

- Yes	
- No	SKIP TO Q.21
- Don't know/No answer	SKIP TO Q.21

19. (IF YES TO 18a, b, c, OR d) Which of the following types of out-of-pocket expenses [do/did] you typically pay in caring for your [Q.6 response]?
READ IN SEQUENCE - CODE ALL THAT APPLY; PROBE: Anything else?

- Prescription medications/drugs
- Non-prescription medications
- Nursing services
- Professional services/therapy, such as psychological services and assessments, counselling, physiotherapy or occupational therapy
- Personal care worker (someone who helps with things like personal grooming)
- Ambulance services
- Transportation, such as gasoline, taxis or public transit
- Homemaking, such as housecleaning and light meal preparation
- Someone who allows you to take a break/respite

VOLUNTEERED

- None SKIP TO Q.21
- Other (SPECIFY ________________________)
- Don't know/No answer SKIP TO Q.21

20. And approximately how much [do/did] you spend on average on a monthly basis to provide care for your [Q.6 response]?

RECORD AMOUNT: $ ____________

IF RESPONDENT HAS TROUBLE ESTIMATING, PROMPT BY READING THE CATEGORIES PROVIDED

- Up to $100 per month
- $100 to $200
- $201 to $300
- $301 to $400
- $401 to $500
- More than $500 per month

VOLUNTEERED

- Not spending on a regular basis
- Don't know/No answer

D. Formal Services

SHORT TERM CURRENT CAREGIVERS (LESS THAN 12 MONTHS), IFQ9 IS LESS THAN 12 MONTHS

21a. During the past [few (IF Q9 IS 6 MONTHS OR LESS)/several (IF Q9 IS 6 MONTHS TO 12 MONTHS)] months has your [Q.6 response] received some form of formal or professional home or community care services, either at no charge or paid for?

- Yes
- No SKIP TO Q.25

VOLUNTEERED
- Previously received such services SKIP TO Q.25
- Don't know/No answer SKIP TO Q.25

SHORT TERM PAST CAREGIVERS (LESS THAN 12 MONTHS), IFQ9 IS LESS THAN 12 MONTHS

21b. During the time you were a caregiver has your [Q.6 response] received some form of formal or professional home or community care services, (either at no charge or paid for)?

- Yes
- No SKIP TO Q.25

VOLUNTEERED
- Previously received such services SKIP TO Q.25
- Don't know/No answer SKIP TO Q.25

LONG TERM CURRENT CAREGIVERS (MORE THAN 12 MONTHS), IFQ9 IS MORE THAN 12 MONTHS

21c. In the past 12 months, has your [Q.6 response] received some form of formal or professional home or community care services, either at no charge or paid for?

- Yes
- No SKIP TO Q.25

VOLUNTEERED
- Previously received such services SKIP TO Q.25
- Don't know/No answer SKIP TO Q.25

LONG TERM PAST CAREGIVERS (MORE THAN 12 MONTHS), IFQ9 IS MORE THAN 12 MONTHS

21d. During the last year you were a caregiver, has your [Q.6 response] received some form of formal or professional home or community care services, either at no charge or paid for?

- Yes
- No SKIP TO Q.25

VOLUNTEERED
- Previously received such services SKIP TO Q.25
- Don't know/No answer SKIP TO Q.25

22. (IF YES TO Q21a, b, c, OR d) What type of services [are/were] provided to your [q6. response]?
DO NOT READ - CODE ALL THAT APPLY

- Nursing visits
- Physiotherapy
- Occupational therapy
- Social work
- Psychologist
- Nutrition
- Personal care worker (someone who helps with things like personal grooming)
- Ambulance services
- Homemaking, such as housecleaning and light meal preparation
- Psychiatric day hospital program
- Clubhouse program
- Counseling/mental health counseling
- Medical care/doctor
- Other (SPECIFY ____________________)
- None SKIP TO Q.25
- Don't know/No answer SKIP TO Q.25

23. [Are/were] any of the services you just mentioned received free of charge?
READ CODES FROM Q.22 IF NECESSARY - CODE ONLY FOR THOSE MENTIONED IN Q.22

- Nursing visits
- Physiotherapy
- Occupational therapy
- Social work
- Psychologist
- Nutrition
- Personal care worker (someone who helps with things like personal grooming)
- Ambulance services
- Homemaking, such as housecleaning and light meal preparation
- Psychiatric day hospital program
- Clubhouse program
- Counseling/mental health counseling
- Medical care/doctor
- Other (SPECIFY ____________________)
- None
- Don't know/No answer

24. How well have these services met the needs of your [Q.6 response]? Would you say these services have met (ENTER GENDER AS PER Q6N) (his or her) needs:

- Very well
- Generally OK
- Not very well
- Not at all

VOLUNTEERED
- Depends
- Don't know/No answer

25. Are there any [additional] types of formal home or community care services that [would be/would have been] of real help to your [q6 response]?

- Yes	
- No	SKIP TO Q.27
VOLUNTEERED	
- Depends/possibly	
- Don't know/No answer	SKIP TO Q.27

26. (IF YES/DEPENDS) What type or types of home or community care [would be/would have been] of most help?
DO NOT READ - CODE ALL THAT APPLY

- Nursing visits
- Physiotherapy
- Occupational therapy
- Social work
- Psychologist
- Nutrition
- Personal care worker
- Ambulance services
- Homemaking, such as housecleaning and light meal preparation
- Psychiatric day hospital
- Clubhouse program
- Counseling/mental health counseling
- Medical care/doctor
- Other (SPECIFY ____________________)
- Don't know/No answer

27. Do you feel your [Q.6 response] [would be/would have been] better cared for in a hospital or a supervised residential facility?

- Yes
- No

VOLUNTEERED
- Depends
- Don't know/No answer

E. Coping with Caregiving

I'd now like to ask you about your experience as a caregiver .

28. Overall, how well do you feel you [are/were] coping with the responsibilities of caring for your [Q.6 response]? Would you say you [are/were] coping:

- Very well
- Generally OK
- Not very well
- Not well at all

VOLUNTEERED
- Depends
- Don't know/No answer

30. To what extent have you experienced personal difficulties of your own as a result of your caregiving in terms of each of the following? Would you say you have experienced significant difficulties, some difficulties, few difficulties, or none at all in terms of your own:
REPEAT SCALE IF NECESSARY

a. Finances
b. Mental health
c. Physical health
d. Balancing personal/family needs

- Significant difficulties
- Some difficulties
- Few difficulties
- None at all

VOLUNTEERED
- Don't know/No answer

31. How often, if at all, [do/did] you feel like you need a break from your caregiving responsibilities? Would you say you [feel/felt] this way:

- Frequently
- Occasionally
- Rarely
- Never

VOLUNTEERED
- Don't know/No answer

31a. How often, if at all, [do/did] you get a break from your caregiving responsibilities? Would you say you [get/got] it:

- Frequently
- Occasionally
- Rarely
- Never (GO TO Q 32)

VOLUNTEERED
- Don't know/No answer

31b. From whom do you get assistance if you need a break?
DO NOT READ – CODE ALL THAT APPLY

- Family member
- Friend
- Neighbour
- Trained volunteer (e.g. friendly visitor)
- Formal help (paid or government)
- Utilized respite service
- Other (SPECIFY)
- DK/Refused

F. Employment Status and Impacts

To finish up, I would like to ask you a few questions about you and your household for statistical purposes only. Please be assured that your answers will remain completely confidential.

32. Which one of the following best describes your employment situation?
READ - CODE ONE ONLY

- Employed, Full time for pay
- Employed, part time for pay
- Self-employed
- Currently seeking work
- Homemaker
- Student
- Retired

VOLUNTEERED

- Other (SPECIFY ______________________)
- Don't Know SKIP TO Q.38

33. (IF HOMEMAKER/RETIRED) Have you quit your job or retired early in order to provide care to your [Q.6 response]?
IF "YES" – PROBE Did you retire or resign?

- Yes – quit	SKIP TO Q.37
- Yes - retired	SKIP TO Q.37
- No	SKIP TO Q.38
- No answer/Refuse	SKIP TO Q.38

34. Has your employment situation changed in any way as a result of caring for your [INSERT RESPONSE FROM Q.6] ?

- Yes
- No
- Don't know/No answer

35. (IF EMPLOYED PART/FULL TIME/SELF-EMPLOYED – OTHERS GO TO Q.38) To what extent has caring for your [INSERT RESPONSE FROM Q.6] disrupted or interfered with your job? Would you say there has been

- Significant disruption
- Some disruption
- Minor disruption
- None at all (SKIP TO Q38)

VOLUNTEERED

- Don't know/No answer

36. Has your employer been flexible in adjusting your work hours or responsibilities to accommodate caring for your [INSERT RESPONSE FROM Q.6]
?

- Yes
- No

VOLUNTEERED

- Not applicable/self-employed
- Don't know/No answer

37. To what extent [would/would have] each of the following options in your work situation help you in balancing caring for your [INSERT RESPONSE FROM Q.6] and work responsibilities? Starting with ___________, would this [be/have been] very helpful, somewhat helpful, not very helpful or not at all helpful?

a. Flexible work hours

b. Leave of absence without pay

c. Short term job and income protection

- Very helpful
- Somewhat helpful
- Not very helpful
- Not at all helpful

VOLUNTEERED

- Already have this
- Not applicable (e.g. self-employed)
- Depends
- Don't know/No answer

38. Is there anything else that you feel [would make/would have made] a difference in helping you handle caring for your [INSERT RESPONSE FROM Q.6], that has not already been covered in this survey? (Not necessarily job related)
SPECIFY

____

- Nothing else
- Don't know/No answer

39. In which of the following age categories can I place you?
READ

- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 and over
- No Response/Refused

40. What is your mother tongue, that is, the language you first learned at home?
CODE ONE ONLY

- English
- French
- Other (SPECIFY ____________________)
- No response/Refused

40N. Who else lives with you in your home [other than your Q.6 response (IF Q2a or Q2b IS IN MY OWN HOME]? (RECORD ALL MENTIONS)

- No one else (SKIP TO Q41)
- Wife
- Husband
- Spouse/partner (includes common law/same sex partner)
- Grandfather
- Grandmother
- Great-grandfather
- Great-grandmother
- Mother
- Father
- Mother-in-law
- Father-in-law
- Sister
- Brother
- Sister-in-law
- Brother-in-law
- Son
- Daughter
- Son-in-law
- Daughter-in-law
- Step-father
- Step-mother
- Step-son
- Step-daughter
- Aunt
- Uncle
- Cousin
- Niece
- Nephew
- Roommate
- Other (SPECIFY)
- Refused

ASK FOR EACH OF THOSE IN Q.40N, WHO CAN BE MORE THAN ONE.

41a. You mentioned that your [Q40 response] lives in your home. How many [Q40 response]s live with you, is it one or more?

- One
- Two
- Three
- Other (SPECIFY)

41b. ASK IF HAVE CHILDREN (SISTER, BROTHER, SON, DAUGHTER, STEP-SON, STEP-DAUGHTER, NIECE, NEPHEW) IN Q.40N.
- How many children under 16 live with you?

41. For statistical purposes only, we need information about your household income. Please tell me which of the following categories applies to your total household income for the year 2003? READ - CODE ONE ONLY

- Less than $25,000
- $25,000 to$34,999
- $35,000 to $44, 999
- $45,000 to $54, 999
- $55,000 to 74, 999
- $75,000 or more

VOLUNTEERED
- Don't Know/Refused

42. Would you identify yourself as Non-Aboriginal or Aboriginal, that is, are you of First Nations, Inuit, or Métis descent?

1) Non-Aboriginal (SKIP TO Q 43)
2) Aboriginal (First Nations, Inuit, or Métis)
VOLUNTEERED
3) DK/Refused (SKIP TO Q 43)

42a. Which Aboriginal group do you belong to - First Nations, Inuit, or Métis?

1) First Nations
2) Inuit (skip to q 43)
3) Métis (skip to q 43)
VOLUNTEERED
4) DK/Refused (skip to q 43)

42b. In the last 12 months, have you lived primarily on or off reserve?

1) on
2) off
VOLUNTEERED
3) DK/Refused

43. And finally, may I have the first three digits of your postal code?
(NEW BRUNSWICK ONLY:) And finally, may I have the six digits of your postal code?
RECORD

___ ___ ___

This completes the survey. Do you know of ANYONE ELSE who provides unpaid care for someone with a mental illness in a non-institutional setting such as their home and who might be interested in participating in this study?

IF YES, RECORD NAME AND NUMBER OF REFERRAL **AND** NAME AND NUMBER OF REFERRING INDIVIDUAL.

IF NAME NOT GIVEN AT REFERRAL: In case my supervisor would like to verify that I conducted this interview, may I have your first name?

First Name: ______________________________

On behalf of Health Canada, thank you very much for your cooperation.

RECORD:

44. Province/Territory

- Alberta
- British Columbia
- Manitoba
- New Brunswick
- Newfoundland
- Nova Scotia
- Ontario
- Prince Edward Island
- Quebec
- Saskatchewan
- NWT
- Yukon
- Nunavut

45. Gender

- Male
- Female

46. Language of interview

- English
- French

APPENDIX B: METHODS TABLES

APPENDIX B: METHODS TABLES

Table B1: Caregiver's Gender and Relationship to the Care Receiver [survey question 6 (care receiver's relationship) and question 45 (caregiver gender)]

CAREGIVER	RECODING
MALE SPOUSE/ PARTNER	0 = Not male spouse 1 = Male spouse [includes males caring for legal and common-law, hetero- and homosexual partners]
FEMALE SPOUSE/ PARTNER	0 = Not female spouse 1 = Female spouse [includes females caring for legal and common-law, hetero- and homosexual partners]
FATHER	0 = Not father 1 = Father [includes males caring for son or daughter]
MOTHER	0 = Not mother 1 = Mother [includes females caring for son or daughter]
FATHER-IN-LAW*	0 = Not father-in-law 1 = Father-in-law [includes males caring for son-in-law or daughter-in-law]
MOTHER-IN-LAW	0 = Not mother-in-law 1 = Mother-in-law [includes females caring for son-in-law or daughter-in-law]
STEPFATHER*	0 = Not stepfather 1 = Stepfather [includes males caring for stepson or stepdaughter]
STEPMOTHER	0 = Not stepmother 1 = Stepmother [includes females caring for stepson or stepdaughter]
GRANDSON*	0 = Not grandson 1 = Grandson [includes males caring for grandfather or grandmother]
GRANDDAUGHTER	0 = Not granddaughter 1 = Granddaughter [includes females caring for grandfather or grandmother]
GREAT-GRANDSON	0 = Not great grandson 1 = Great grandson [includes males caring for great grandfather or great grandmother]
GREAT-GRANDDAUGHTER*	0 = Not great granddaughter 1 = Great granddaughter [includes females caring for grandfather or grandmother]
SON	0 = Not son 1 = Son [includes males caring for father or mother]
DAUGHTER	0 = Not daughter 1 = Daughter [includes females caring for father or mother]
SON-IN-LAW	0 = Not son-in-law 1 = Son-in-law [includes males caring for father-in-law or mother-in-law]
DAUGHTER-IN-LAW	0 = Not daughter-in-law 1 = Daughter in-law [includes females caring for father-in-law or mother-in-law]

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Table B1 (Continued): Caregiver's Gender and Relationship to the Care Receiver [survey question 6 (care receiver's relationship) and question 45 (caregiver gender)]

BROTHER	0 = Not brother 1 = Brother [includes males caring for brother or sister]
SISTER	0 = Not sister 1 = Sister [includes females caring for brother or sister]
STEPSON	0 = Not stepson 1 = Stepson [includes males caring for stepfather or stepmother]
STEP-DAUGHTER	0 = Not stepdaughter 1 = Stepdaughter [includes females caring for stepfather or stepmother]
BROTHER-IN-LAW	0 = Not brother-in-law 1 = Brother -in-law [includes males caring for brother-in-law or sister-in-law]
SISTER-IN-LAW	0 = Not sister-in-law 1 = Sister-in-law [includes females caring for brother-in-law or sister-in-law]
NEPHEW	0 = Not Nephew 1 = Nephew [includes males caring for uncle or aunt]
NIECE	0 = Not niece 1 = Niece [includes females caring for uncle or aunt]
UNCLE*	0 = Not uncle 1 = Uncle [includes males caring for niece or nephew]
AUNT	0 = Not aunt 1 = Aunt [includes females caring for niece or nephew]
MALE COUSIN*	0 = Not male cousin 1 = Male cousin [includes males caring for male or female cousins]
FEMALE COUSIN*	0 = Not female cousin 1 = Female cousin [includes females caring for male or female cousins]
GRANDFATHER*	0 = Not grandfather 1 = Grandfather [includes males caring for male or female grandchildren]
GRANDMOTHER	0 = Not grandmother 1 = Grandmother [includes females caring for male or female grandchildren]
MALE UNRELATED	0 = Not male unrelated 1 = Male unrelated [[includes males caring for a male or female roommate, friend, neighbour, client, or other unrelated person]
FEMALE UNRELATED	0 = Not female unrelated 1 = Female unrelated [[includes females caring for a male or female roommate, friend, neighbour, client, or other unrelated person]

* Categories not included in survey sample

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Table B2 Caregiver Costs

Caregiver Cost Variable	Recoding (original values are bracketed)
Employment- Related Costs	
Quit or Retired Early for Caregiving	0 = No 1 = Yes [includes both 'quit' & 'retired early for caregiving']
'Significant' Job Disruption	0 = Not 'significant' (according to description chosen by caregiver) [includes 'some,' 'minor,' and 'no disruption'] 1 = 'Significant' (according to description chosen by caregiver)
Out-of-pocket Costs	
>$400 Per Month In Out-of-pocket Cost	0 = Not over $400/month [includes 'up to $100,' '$101-$200,' & '$201-$300'] 1 = Over $400/month [includes '$401-$500' & '>$500']
'Significant' Financial Difficulty	0 = Not 'significant' (according to description chosen by caregiver) [includes 'some,' 'few,' and 'no difficulties'] 1 = 'Significant' (according to description chosen by caregiver)
Unpaid Labour Costs	
High Unpaid Labour	0 = Not high activity [includes 'medium,' 'next lowest,' and 'lowest'] 1 = High activity [includes 'highest' and 'next highest' activity levels]

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Table B3: Descriptors of Caregiver

Caregiver characteristics	Recoding (original values are bracketed)
Gender of the caregiver	0 = Male [originally 1] 1 = Female [originally 2]
Spouse in the home?	0 = No 1 =Yes [includes legal and common-law, hetero- and homosexual partners]
Children under 16 present?	0 = No 1 =Yes [includes any number of children under 16 years of age that live with the caregiver]
Other caregiving for ill or disabled persons present?	0 = No 1 = Yes [includes any number of other ill or disabled persons that the caregiver was/is caring for]
Labour Force Status	0 = Not employed [includes currently seeking work, homemaker, student, and disabled/unable to work] 1 = Employed [includes fulltime, part time, and self employed] 2 = Retired
Age of Caregiver	1 = 18-24 2 = 25-34 3 = 35-44 4 = 45-54 5 = 55-64 6 = 65 and over

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Table B4: Descriptors of Care Receiver, & Dyad

Care Receiver Descriptors	
Gender Of The Care Receiver	0 = Male [originally 1] 1 = Female [originally 2]
Age of Care Receiver	1 = 18-24 2 = 25-34 3 = 35-44 4 = 45-54 5 = 55-64 6 = 65-74 7 = 75-84 8 = 85 and older
Primary Mental Illness	1 = Mood disorder 2 = Schizophrenia 3 = Anxiety disorder 4 = Personality disorder 5 = Eating disorder
Illness Duration	1 = Short term/Acute (less than 3 months) 2 = Medium term (three to six months) 3 = Long term (longer than six months) 4 = Uncertain/cannot say at this time
Dyad Descriptors	
Duration of Caregiving	1 = Less than a month 2 = 1 to 3 months 3 = 4 to 6 months 4 = 7 to 12 months 5 = 1-2 yrs. 6 = 3-5 yrs. 7 = 6-10 yrs. 8 = More than 10 yrs.
Geographic proximity	0 = Elsewhere [includes care receiver's home and elsewhere] 1 = Caregiver's home
Relationship	See Table B1

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